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FOLLOW-UP OF THE HIGH RISK INFANT

MONTANA PERINATAL PROGRAM

PREVENTIVE HEALTH SERVICES BUREAU

MONTANA DEPARTMENT OF HEALTH & ENVIRONMENTAL SCIENCES
COGSWELL BUILDING HELENA, MONTANA

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OF
THE HIGH RISK INFANT

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JULY 1987

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FOREWARD

The importance of follow-up by community health nurses to families of high risk infants is obvious. However (and fortunately), the incidence of many of the conditions which cause infants to be high risk is not sufficient for the community health nurse to maintain a high level of expertise in the technical aspects of care.

The human, caring things we as professionals can do to assist families as they care for the child who is "different" are part and parcel of nursing in any setting. They should not be lost in our efforts to focus on the disease or condition which labels the child "high risk."

This manual blends the best of both worlds. Nursing care plans provide detailed guidance for the more usual "at risk" conditions, while at the same time providing information about supportive care of the family who may be grieving for the loss of their "longed-for" or "envisioned" child.

The outline format of the manual ensures that information is easily accessible. The loose leaf feature makes it possible to photocopy care plans for incorporation into charts and to update sections as new information becomes available. This is your manual -- use it, share it, critique it. It represents a significant effort to provide guidelines for community health nurses in an important component of their care to families.

Maxine Ferguson, R.N., M.N.
Nurse Coordinator
Montana Perinatal Program
July, 1987

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SUGGESTIONS FOR THE USE OF THIS MANUAL

1. Read the information sheets for the infant's medical diagnosis/es.

2. Develop a baseline assessment for:

   -- Infant - Use Data Base for High Risk Infant (Chapter: Initial Assessment)

   -- Family - Use Care Plan for Families with a High Risk Infant (Chapter: Initial Assessment)

   -- Make a copy for family's chart of any printed instructions for care of high risk infant sent from hospital.

3. Make copy for infant's chart of Nursing Care Plan for infant's diagnosis/-es.

4. You will find a list of several interventions for various problems. Choose the interventions which are appropriate and realistic for your individual client. As the interventions are completed, initial and date on the Nursing Care Plan.

5. Offer resources from Resources section as appropriate.

6. Use the hospital as a resource, if needed, for nursing consultation on specific infant's plan of care.

7. All nursing care for prevention and health maintenance (diet, growth and development, immunizations, discipline, etc.) should be addressed for each family.

   Note: The care plans address the primary nursing diagnosis/es for that particular medical diagnosis. Each individual infant and/or family may have specific problems and needs which should be addressed.

   -- The plan of care is not meant to be all inclusive. Other interventions can be used very effectively.

   -- The care plans can be modified based on interventions used by other members of the infant's health care team (e.g., P.T., R.T., O.T., nutritionist, etc.)

8. An infant with more than one medical problem may need more than one care plan.

II. THE HIGH RISK INFANT AND HIS/HER FAMILY
INITIAL ASSESSMENT

The high-risk infant and his/her family face a tremendous task following hospitalization. These families have exhausted many of their financial and social resources and coping skills during the series of crises following their infant's birth. Support people both within the health care system and within the family's support system tend to withdraw after the infant is released from the hospital. While the acute or crisis stage is over, the infant and his/her family still face tremendous problems. The total care of the infant becomes the responsibility of the family.

Families may experience severe stress in meeting the demands of the infant and continuing to meet the needs and demands of the other family members. In the first weeks after the infant is home, the family members must make the adjustments necessary to accommodate the new family member, as well as incorporate the care needs of the infant into the family routine. The family of the high risk infant faces all the normal postnatal tasks even though the infant may be 4-6 months of age.

Because the infant and parents are often separated at birth and an atmosphere of crisis prevails, the normal developmental tasks of "taking in", "taking on", and "taking hold" (Rubin, 1972) are postponed. If the parents have the opportunity to "room-in" with the infant before discharge, or if they are encouraged to participate in the care of the infant in the hospital nursery, the tasks begin at this time. If the infant is discharged home, without an opportunity to become actively involved in the infant's care, these tasks take place at home.

When these tasks take place at home, the community health nurse and other family support systems need to encourage parents to carry out the behaviors which allow them to complete the tasks. For the "taking in" phase, parents need to talk about the birth of their baby. They need to review as much as possible about the birth. This can be encouraged by asking parents to describe everything they remember about the birth day. Encourage them to ask questions which they have held off asking during the crisis phase. This is critical assessment information.

The "taking on" phase involves parents beginning to explore what needs to be done to care for their infant. During this phase, the community health nurse needs to review with the parent any questions or concerns about infant care and any special care their infant might need. It is essential to successful completion of the "taking on" phase that the community health nurse communicates to the parents, his/her confidence that they will care for their infant successfully. BE POSITIVE in your approach to the parents.

The "taking hold" phase involves the parents' incorporation of the infant and his/her care into family life. Parents usually need positive feedback about their efforts. At this time, parents may seek alternative approaches to problems that have not been resolved. This requires the community health nurse to identify what has been tried and why the parents feel that it did not work. The nurse may then either offer another solution, contact other resources for possible solutions or refer parents to support groups who may generate solutions. This requires creativity and patience on the part of both the parents and the nurse. It may take several trial solutions to find one that works in a particular family.

Common problems for families of high-risk infants include:

1. Divorce
2. Low-income (may have exhausted financial resources to care for infant)
3. Single parents
4. Immature parents
5. Weak/non-existent support systems
6. Unresolved grief work
7. Slow/impaired adaptation to parenting
8. Failure-to-thrive (non-physiologic)
9. Neglect, physical and/or emotional abuse

The priorities in working with these high risk families include a thorough initial baseline assessment of home, family, support system, community resources and infant. The following care plan includes a complete assessment guide as well as nursing diagnoses, goals, and plans. This care plan should be used with all families of high risk infants.

DATA BASE FOR HIGH-RISK INFANT*

Name of Infant: ______________________________

Name of Parents or Parent: ______________________________

Address: ______________________________ Phone: ______________

____

Health Care Provider: ____________________ Phone: ______________

Address: ______________________________ Date of last visit ________

Insurance/Medicaid Number: ______________________________

Religious Preference: ______________________________

Infant Baptised: Yes ____ No ____

Does anyone in house smoke? Yes ____ No ____

If yes, what kind: pipe, cigar, cigarette? ______________

How many pipes, cigars, cigarettes/day? ______________

Infant's Date of Birth: ____________________ EDC: ____________

Discharge date ______________________________

Gestational Age (by clinical exam) at birth: ______________________________
(May be on referral form, if not, may be requested from tertiary care center)

Birth weight: ______________ Birth length: ______________

Discharge weight ______________________________

Birth Head Circumference: ______________

Parental description of birth (length of labor, use of medications during labor, use of forceps, Cesarean or vaginal delivery, use of fetal monitor, rupture of bag of waters, parents' feelings about delivery).

*This data base was developed by the author for this manual.

Parental description of postpartum period (were parents able to see baby before transfer, type and frequency of contacts with Intensive Care Nursery, summary of progress when in ICN, parents' major concerns in bringing infant home, parents' preparation for discharge).

GROWTH AND DEVELOPMENT
(Adapted from Washington Guide)

Guidelines

1. Baby must be awake and alert for accurate assessment.

2. This Guide outlines expected behaviors of a 1-3 month old (4-12 week old) infant who was a full-term, healthy newborn. It is not adjusted for prematurity. You must make the adjustment.

3. How to adjust for age of individual premature baby:

   a. Identify baby's gestational age at birth, i.e., 30 weeks.

   b. Subtract gestational age from normal full-term gestational age of 40 weeks (40-30 = 10 weeks prematurity).

   c. Subtract number of weeks of prematurity from baby's current age (weeks since birth) to determine the level of growth and development at which s/he should be functioning:

Present age:	18 weeks
Minus number of weeks of prematurity:	-10 weeks
Equals expected level of function:	8 weeks

   d. Thus, the infant who was born 10 weeks early will be expected at 18 weeks of age to function as a normal 8 week old infant.

   e. As time goes on, this gap diminishes. By the time the child reaches school age, the gap has generally disappeared. The greater the degree of prematurity, the greater the delay in reaching developmental milestones in the first years of life.

Examination

EXPECTED TASK	YES	NO
1. Palmar grasp.		
2. Moro Reflex.		
3. Follows object through all planes.		
4. Head erect and bobbing in sitting position.		
5. Turns head from side to side when prone.		
6. Sucking reflex present.		
7. Rooting reflex present.		
8. Coordinates sucking, swallowing and breathing.		
9. Quiets when picked up.		
10. Regards face of others.		
11. Movement of eyes, respiration rate or body activity changes when bell is rung close to infant's head.		
12. Smiles when socially stimulated.		
13. Has facial, vocal and generalized body responses to faces.		
14. Reacts differentially to adult voices.		
15. Makes "pleasure" sounds that consist of soft vowels.		
16. Makes "sucking" sounds.		
17. Crying can be differentiated for discomfort, pain and hunger as reported by parent.		
18. An "A" sound as in cat, is commonly heard in distress crying.		
19. Draws attention by crying.		
20. Infant desires what is pleasant and wishes to avoid unpleasant situations.		
21. Beginning to "wiggle" around.		

SKIN CARE

Bath Routine ____

____

Disposable diapers ____________ Cloth diapers ____________

Special Skin Care Needs Related to Health Care Problem ____________

____

____

INFANT'S SLEEP/REST PATTERN

Naps: Yes ____ No ____ Time of Naps ________ Length of Naps ____

Time infant usually goes to bed for the night: ________________

How often does infant wake during night: ________________

Length of time awake during night: ________________

Calming measures ________________________________

NUTRITION

Breast fed ______ Bottle fed ______ Type of nipple used ________

Type of formula ____________ # of calories/oz. ____________

Formula thickened with cereal: Yes ____ Type ____ No ____

How often is infant fed __________ Length of feeding __________

Vitamin supplements: Yes _____ No _____ If yes, what supplements: _____

____

Urine: Frequency ______________ Character ______________

Stools: Frequency ______________ Character ______________

Special Nutritional Needs Related to Health Care Problem ____________

____

____

MEDICATIONS

Medications	Amount	Frequency	Route	Usual Routine for Administration
1.				
2.				
3.				
4.				
5.				
6.				

TREATMENTS

Treatment	Frequency	Community Supply Source
1.		
2.		
3.		
4.		
5.		
6.		

NURSING CARE PLAN FOR FAMILIES OF HIGH-RISK INFANTS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Parent Assessment: Physiologic Signs: -- Elevated heart rate, blood pressure and/or respiratory rate. -- Difficulty sleeping. -- Cool, clammy skin. -- Dilated pupils. -- Flushing. -- Dry mouth. -- Urinary frequency. -- Body aches and pains. -- Voice shaking. -- Tremors. -- Restlessness. -- Fainting. -- Nausea/vomiting. Emotional Signs: -- Fear and/or apprehension. -- Nervousness. -- Helplessness and lack of self-confidence.	Parental Anxiety related to concerns about ability to meet infant's needs.	Parents are able to verbalize their concerns about infant care. Parents able to demonstrate care of infant with confidence.	1. Assess degree of anxiety (mild, moderate, severe, panic). For definition of mild, etc. see p. 82-83 of Carpenito, I.J. Nursing Diagnosis: Application to Clinical Practice. 2. Support and encourage parents in the current care they are giving their infant. 3. If the parents are unhappy with a solution they are using, encourage them that a solution can be found. 4. Encourage parents to discuss what their expectations of their infant and his/her care were. Were their expectations realistic? What can be done now to either change their expectations or to change the situation? 5. If parents have previous infant care experiences, what did they do in infant care which would be useful now? 6. Reduce or eliminate the use of non-productive defense mechanisms (such as, depression, violence, denial, unproductive anger or physical complaints which have no known organic base). For a summary of methods which can be used to reduce the use of these defense mechanisms, see Carpenito, L.J., Nursing Diagnosis: Application to Clinical Practice, Lippencott, J.B., Philadelphia, 1983. -- Provide reassurance and comfort. -- Decrease sensory stimulation.	

NURSING CARE PLAN FOR FAMILIES OF HIGH-RISK INFANTS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
-- Irritability. -- Outbursts of anger. -- Crying. -- Criticisms or blame of self or others. -- Withdrawal. -- Depression. Cognitive Signs: -- Memory lapses. -- Poor concentration. -- Orientation to past rather than present or future.			7. Begin teaching about infant care when anxiety is reduced. 8. Teach use of relaxation techniques. 9. Teach use of problem-solving techniques: -- Anticipatory preparation - Mental rehearsal of possible outcomes or consequences. -- Goal setting - Help parents set realistic goals for themselves and their infant. -- Information seeking - Help parents with reading, support groups and other types of accurate information about their infant's health problem. -- Mastery - Support parents' efforts to master skills necessary for care of their infant. -- Help Seeking - Give the parents resources and local support groups. Encourage the parents to ask questions and seek information. 10. Do not encourage the parents to focus on all the implications of their infant's health problem and care at once - it may be too overwhelming. 11. Avoid false reassurance such as "It will be OK" or "Don't worry".	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			12. Clarify misinformation or misunderstanding - Make sure your information is current and accurate. 13. Assist parents to find respite care so they can get out regularly. 14. Teach parents infant CPR.	
Sibling Assessment: Increased crying, clinging, demands for attentions. Increased motor activity. Isolation from other family members. Refusal to look at, hold, or talk to infant. Aggression. Regression. Habit formation (nail biting, etc.) Pattern disruptions (waking at night, etc.) Expresses anger at infant.	Alterations in family processes: sibling anxiety, rivalry, and neglect related to normal fears in childhood, parents' anxiety, lack of attention.	Promote family's interaction as a cohesive unit. Involve siblings in life of the infant. Assist parents in recognizing siblings' needs for love and attention. Encourage parents in meeting siblings' needs for love and individual attention.	1. Involve other children in infant care as is appropriate to their age and developmental level. -- Provide opportunities for siblings to be in physical contact with infant. -- Involve siblings in play activities with infant. -- Involve children in bringing supplies, observing infant for short periods of time while parents are busy, or in actual care-giving whenever possible. -- Give plenty of positive reinforcement for these activities. 2. Keep infant visible within the family constellation. -- Move infant from room to room to keep him "where the action is". -- Take infant along on family outings. 3. Help parents identify special time that they can spend with other children when infant will not be involved. 4. Encourage siblings to talk about guilt, fears, anger, and correct any misunderstandings.	

NURSING CARE PLAN FOR FAMILIES OF HIGH-RISK INFANTS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Parents discuss their feelings of loss. Expressions Of: -- Ambivalence -- Denial -- Fear -- Concerns -- Anger -- Depression -- Guilt -- Indigestion -- Nausea/vomiting -- Loss of appetite -- Weight gain/loss -- Constipation or diarrhea -- Loss of sleep or preoccupation with sleep -- Fatigue	Grieving: Stage of grief related to loss of "ideal" image of infant, difficulty in separating from crisis periods when infant was in life-threatening situation and potential for chronic grief state when infant doesn't meet parental, societal or developmental expectations.	Short Term - Parents able to verbalize feelings associated with loss. Long Term - Family able to "work through" grief. Long Term - Family able to provide care. Long Term - Family able to find hope in infant's accomplishments.	1. Assess for factors which may impair grief work. -- Lack of support system. -- Denial, shock, anger, guilt, fear, depression. -- Dependency. -- Inability to grieve (cultural, social, related to age as in siblings). -- History of previous emotional illness. -- Loss of significant other at an early age. 2. Be supportive of family members' grief reactions. 3. Explain normal grief reactions: (Engel, 1964) -- Shock and disbelief. -- Anger. -- Developing awareness. -- Restitution. 4. Support the family's functioning. 5. Encourage family's exploration of their feelings about their infant and the infant's care needs. 6. Encourage various family members to talk about their feelings with one another and to support one another. 7. Recognize and reinforce each family member's role in caring for their infant.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			8. Promote grief work with each type of response: Denial: -- Recognize that this is a useful coping strategy. -- Make sure infant's care is being carried out during periods of denial. -- Explain special care needs of their infant as part of normal infant care because each infant has special care needs of one kind or another. -- Explain the use of denial on the part of one family member to other family members. Isolation: (Very common grief reaction among families whose infant has observable physical problem) -- Convey a feeling of acceptance by allowing grief. -- Encourage open, honest communications. -- Reinforce feelings of self-worth by respecting privacy. -- Help parents plan first outing so very little goes wrong. This promotes self-confidence. -- Role-play potentially stressful situations. -- Show an attitude of acceptance toward infant by calling him by his name, commenting on his attractive features or behaviors.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Promote community acceptance of people with handicaps through community education programs and awareness of needs of handicapped individuals in community.	
			Depression:	
			-- Reinforce parent's self-esteem.	
			-- Encourage parents to discuss feelings of being overwhelmed or depressed.	
			-- Encourage parents to get adequate rest.	
			-- Assist parents in planning time for regular exercise.	
			-- Encourage a diet which is well-balanced.	
			-- Look for any indications of suicidal behavior (frequent statements of intent, revealed plan) and refer to counseling.	
			Anger:	
			-- Explain to family that this usually replaces denial.	
			-- Encourage family to discuss feelings of anger.	
			-- Help family identify sources of frustration and anger and relate to subsequent behavior and actions.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Have angry family members identify actions which will promote constructive resolution of anger (e.g., begin a support group).	
			Guilt:	
			-- Acknowledge parent's view of infant's situation.	
			-- Avoid arguing and participating in the parent's system of "shoulds" and "should nots".	
			-- Help parents move verbally from preoccupation with themselves or infant to future orientation.	
			Fear:	
			-- Help parents role play through worst possible events.	
			-- Encourage parents to learn about their child's health care needs.	
			-- Reinforce parents efforts at viewing infant as "normal with some unusual needs."	
			Rejection: (Very common reaction of parents to an infant with special needs).	
			-- Assist parents to look at all of their options in planning for infant's care.	
			-- Avoid placing value judgements on family's decisions.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Promote communication and understanding among family members when one member is using rejection and other members are not. -- Family members often know what they can cope with and if they really believe that they can't meet their infant's needs, then support their decision. 9. Promote the grief work of siblings by being honest about the infant's health care needs and by explaining to the children in language they can understand. -- Correct any misunderstandings about the infant which siblings might have had. -- Prepare the siblings for changes in reactions by parents. -- Assist parents to find time for siblings. -- Involve siblings in care of infant appropriate to his developmental level. 10. Teach family signs of resolution of grief. -- Family becomes future oriented and begins to set future goals. 11. Explain that grieving can reoccur when infant fails to meet parental expectations following health crisis (such as illness) or if developmental milestones (such as starting school) must be altered or postponed.	

NURSING CARE PLAN FOR FAMILIES OF HIGH-RISK INFANTS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Family members verbalize fear, anger or anxiety. Family engages in destructive bickering. Family's usual decision making is impaired. One or more family members refuse to participate in the infant's care. Absence of verbal and nonverbal family interaction. Tendency of family to reject or interfere with infant's care needs (e.g.: "forgetting to give medications"). Sudden outburst of emotions without apparent cause and/or emotional lability of family members.	Ineffective coping related to increased demands of caring for infant and changes changes in roles to meet increased care demands.	Short Term - Family members are able to verbalize feelings to community health nurse and to each other. Short Term - Family members are able to participate in care of infant. Short Term - Family members are able to seek help from resources outside the family as needed. Long Term - Family members are able to assist infant to meet normal growth and development needs. Long Term - Family is able to maintain a functional support system for each member.	1. Identify potential problem areas in family's ability to cope with infant's health care needs. -- Burden of caring for infant that has long-term health care problems. -- Potentially disabling nature of infant's health care problems. -- Symptoms which create disfiguring physical changes in infant. -- Social stigma associated with infant's health care problems (especially mental retardation and seizure disorders). -- Financial demands created by infant's medical care, medications and equipment needs. -- Lack of or limited support system available to the family. -- Lack of physical facilities such as electricity, telephone, transportation, running water to meet infant's health care needs. -- Lack of continuity of care among health care professionals. 2. Support family strengths by reinforcing positive behaviors. 3. Involve family members in infant's care by teaching each member.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			4. Involve family in health care planning meetings for their infant.	
			5. Assist the parents to find child-care and/or respite care for infant. Become involved in teaching child care providers to care for infant's special needs.	
			6. Facilitate family communication.	
			7. Refer family to other community resources when family needs exceed community health nurses' ability or time to work on family problems.	
			8. Assist family in developing realistic goals for infant by:	
			-- Encouraging family to have a realistic perspective. Provide accurate information and answers to questions.	
			-- Assisting family to reorganize roles at home and set priorities to maintain family needs and integrity. Reduce stress on family members.	
			-- Referring family to community agencies, home health care organizations and sources of financial aid as needed.	
			9. Provide anticipatory guidance about infant's growth and development needs.	

NURSING CARE PLAN FOR FAMILIES OF HIGH-RISK INFANTS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Parents' ability to perform prescribed procedures with accuracy and competency. Level of cognitive and psychomotor development related to age, ability to read and write, judgement and insight. Presence of sensory deficits in family members. Learning needs as perceived by family. Learning ability - -- Level of education -- Ability to read -- Language barriers Ethnic background -- Health traditions -- Life style Stage of grieving Anxiety on part of parents when providing care Refusal to participate in infant's care Delays seeking medical care for infant when needed	Knowledge deficit related to lack of similar previous life experiences, or lack of knowledge base or inadequate intellectual function or psychological stress	Assess need for teaching. Reduce barriers to learning. Teach skills as necessary. Reinforce positive self-concept as caregiver.	1. Assess family members' need for teaching-reinforce care that family members are doing well. 2. Reduce barriers to learning by: -- Assisting parents to meet basic physiologic needs such as diet, rest, and relaxation. -- Identify parents' stage of grieving both currently and when discharge instructions were given in hospital. *Note: Anger or denial make learning almost impossible. -- Delay teaching if possible to a time when parents have reached "taking on" or "taking hold" phase. -- Adapt teaching strategies to individual family needs. -- Examine parents' health beliefs and their impact on infant's care. -- Encourage family members to express feelings before beginning teaching. 3. Encourage family members' active participation in learning by setting mutually agreed upon goals. 4. Reduce anxiety. *Note: Do not try to change the way parents were taught to do a procedure unless it is obviously unsafe or inaccurate. 5. Implement and evaluate teaching plan.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Misuse of health care system Over-dependence on health care resources to do care that parents could do themselves			6. If parents do not have intellectual or physical capacity to manage health care tasks, seek additional resources to provide care in the home: grandparents, neighbor, community volunteer, or health care professional.	

NURSING CARE PLAN FOR FAMILIES OF HIGH-RISK INFANTS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Parents verbalize feelings of inadequacy, disgust at infant's bodily functions, resentment toward infant and/or disappointment in sex or physical characteristics of infant. Parents do not: -- Hold infant close -- Seek eye to eye contact -- Talk to infant or call infant by name -- Attend to infant's needs -- Ask questions about infant care -- Appear happy - they cry and are sad Parents express: -- Fear that infant will die. -- Intimidation by equipment, procedures, health care professionals discussion of problems. -- Concern about disruption of their lives. -- Guilt. -- Helplessness.	Alteration in parenting: bonding related to increased demands of infant's special health care needs or separation from infant following birth or grieving the loss of a perfect newborn.	Parents will: Demonstrate increased attachment behaviors such as holding close, smiling and talking to infant and seeking eye contact with infant. Initiate an active role in infant care. Begin to verbalize positive feelings toward infant.	1. Assess family for risk factors in relationship to parenting. -- Unwanted pregnancy -- Lack of positive support system -- Lack of positive role model -- Substance abuse -- Marital difficulties -- Life style changes in relationship to parenting role -- Adolescent parent -- Career change (e.g. working outside home to working inside home) 2. Discuss parents' concerns about their child's "differentness" (uniqueness). 3. Point out features about baby that are normal - both her appearance and activities. Comment on the child's beautiful hair, skin, eyes, face, fingers, or whatever is appropriate. Show a great deal of interest in this baby's positive unique features. 4. Encourage parents to hold child and assist them in doing this if necessary. Demonstrate how to cuddle baby despite equipment attached to baby, positioning with pillows or blankets if necessary.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
-- Concern that baby does not love them. -- Overconcern when baby is crying. -- Baby is too demanding. -- Hostility toward baby. -- Lack of support from significant others. -- Multiple physical complaints (usually unfounded) about parent's own health. Parents meet physical needs of infant with great care, but do not meet baby's needs for love, attention, stimulation, or play.			5. Discuss with parents: -- How to play with baby (demonstrate). -- Importance of responding to baby's cries. -- How to provide auditory or visual or tactile stimulation or mobility when these areas are impaired. Stressing extra stimulation in those areas where it can be provided helps to make up for lack of stimulation in areas where it cannot be provided. 6. Discuss need for respite care. Assist in finding sitters or care givers so that parents can get away. 7. Support parents in learning and teach normal infant care as well as special care needs of this infant. 8. Give parents positive reinforcement for the care that they are providing. 9. Role-play potentially awkward situations parents may encounter in public in order to help them cope with questions, stares, and negative reactions to child. 10. Make sure care givers are getting two hours of rest during the day and at least four hours uninterrupted sleep during the night. 11. Explore with parents their comfort level with infant care.	

NURSING CARE PLAN FOR FAMILIES OF HIGH-RISK INFANTS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			12. Encourage parents to use community resources. 13. Assess strengths and weaknesses of family's support system. 14. Assist family in strengthening support system. 15. Refer parents to community support systems. 16. Maintain telephone contact between visits and encourage parents to call with questions or needs. 17. Observe for signs of child abuse: -- Unexplained injuries. -- Not seeking health care appropriately. -- Financial problems. -- Increasing social isolation. -- Increasing marital problems.	

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III. THE INFANT WITH A TERMINAL ILLNESS

Some high risk infants will have a terminal illness while many others will be at greater risk for an early death. The families of high risk infants will be grieving for the loss of their "ideal" infant, the loss of the family's idea of the infant's potential as well as grieving the loss of life. Whenever the infant has a crisis, grief work may be set back or restarted if resolution had been reached. It is critical that the nurse watch for changes in grief status as these will often alter compliance with the infant's treatment plan.

If grief work is incomplete or unrecognized, it can cause severe family disruptions which can ultimately lead to dissolution of the family. This care plan should be used for all families with high risk infants.

NURSING CARE PLAN - POTENTIAL TERMINAL ILLNESS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Anticipatory Grieving Family members express Sadness Depression Shock Anger Fear Denial Guilt Insatiable quest for information about the illness. Seeking out persons who will support a positive outcome. Withdrawal, in order to protect themselves from "bad" news. Questions (voiced/not) about causes of illness. Projection of feelings of guilt on other people. Difficulty in making decisions. Making inappropriate decisions. Anger directed at health care providers, spouse, siblings, or ill child. Overprotectiveness. Permissiveness. Depression and ambivalence. Concerns and lack of acceptance over body image changes.	Grieving related to an anticipated loss of a child.	Parents will be able to express their feelings of grief. Parents will share their questions and concerns. Parents will participate in future decision-making.	1. Refer family to local Hospice group for support. 2. Encourage parents to share their concerns. 3. If parents are seeking information, assist their efforts with sources of accurate information. 4. Support parents' efforts to withdraw until they are ready for more information. 5. Guilt. -- Listen to parents' concerns and communicate your concern. -- Allow for crying (provide privacy, quiet, support). Provide physical contact during crying such as hugging, touching, holding a hand, if parent seems accepting of this behavior. -- Explore methods of resolving guilt. -- Promote direct expression of feelings. 6. Encourage parents to discuss their feelings of loss of a "perfect" child. 7. Assist and support family decision making by offering choices and alternatives where appropriate.	

NURSING CARE PLAN - POTENTIAL TERMINAL ILLNESS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Bargaining.			8. Assist parents by helping to examine the implications of decisions.	
Increased dependency between parents and child.				
Social isolation of family from others.			9. Review information given to family about diagnosis, clarify any misunderstandings.	
Hope that illness will disappear.			10. Encourage parents to resume pre-illness discipline and care of infant and siblings.	
Anxiety.				
Concern for the future.			11. Explore reasons behind guilt and assist parents to look at those reasons realistically.	
Heightened anticipatory grieving during relapses.				
Loss of hope.			12. Anger	
Depression.			-- Allow for crying to release energy.	
Fear of death.			-- Encourage concerned support from significant others.	
Fear of pain.				
Fear of loss of control.			-- Observe for signs of parents' neglecting their own health and/or verbally degrading themselves.	
Fear of isolation and loneliness.				
			-- If anger is expressed toward professionals, listen to parents' concerns and views without taking sides.	
			-- If anger is justified, support parents while they discuss their concerns with the person involved.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Assist parents to find uninterrupted time with siblings.	
			-- Encourage parents to explain illness of child to siblings.	
			-- Involve siblings in care by having them send cards, pictures, cassette tapes of their activities, visits and photographs.	
			13. Encourage parents to share their thoughts and concerns about treatments.	
			14. Involve both parents in care and discussions when appropriate.	
			15. Families need thorough, detailed and repeated explanation of the plan of care.	
			16. Encourage family members to participate in support groups.	
			17. Refer parents to appropriate community financial resources for support.	
			18. Support parents in moving from one grief stage to another.	
			19. Be prepared for exaggerated grief responses during crisis and relapses.	
			20. Assist family to formulate realistic short-term goals and develop reasonable priorities of care.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Terminal Stage and Post-Death	Grieving related to loss of child.	Parents will:	During terminal stage:	
Brief shock		Short Term - Express feelings of grief.	1. Discuss with family their wishes and expectations for the terminal phase.	
Review of relationship parents had with child		Short Term - Utilize available support systems while grieving.	2. Clarify misconceptions and supply correct information about death.	
Indecision		Long Term - Resolve grief work.	3. Use good pain management techniques.	
Social reintegration		Long Term - Begin to act on plans for the future and become future-oriented.	4. Help both parents and infant to maintain a sense of control.	
			5. Support parents at the bedside during death.	
			6. After death, allow family a period of time to say goodbye to infant.	
			7. Support parents as they review their relationship with their infant. Listen for signs of guilt and intervene where possible.	
			8. Refer to hospice if not done prior to infant's death.	
			9. Assist parents in re-evaluation of their roles and support new role activities.	

RESOURCES

THE INFANT WITH A TERMINAL ILLNESS

1. Local Hospice services

2. Compassionate Friends
   P.O. Box 1347
   Oak Brook, Illinois 60521

3. Candlelighters
   2025 I. Street, N.W.
   Washington, D.C. 20006

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IV. THE PREMATURE INFANT

DEFINITION:

Infant born before attaining the 38th week of gestation.

PATHOPHYSIOLOGY:

The smaller the infant, the less chance s/he has to survive. A premature infant weighing 1500 g is 200 times more likely to die than an infant born at term. Medical problems of prematurity occur because organ systems are not mature and because of aggressive treatment technologies necessary to sustain life. The following chart* describes how organ systems are affected by prematurity.

Organ System	Disorders	
	Acute	Chronic
Respiratory system	Respiratory distress syndrome Apnea of prematurity Pneumonia	Bronchopulmonary dysplasia Apnea of prematurity Tracheostomy Subglottic stenosis Croup syndromes Frequent respiratory infections
Cardiocular system	Patent ductus arteriosus Cor pulmonale	Cor pulmonale
Central nervous system	Hypoxic brain damage Intraventricular hemorrhage Seizures	Neurodevelopment disorders Hydrocephalus Seizures
Gastrointestinal system	Necrotizing enterocolitis Jaundice	Malabsorption syndrome Malnutrition Growth retardation
Hematologic system	Anemia	Anemia
Other	---- Sepsis Meningitis Pneumonia	Hernias Retinopathy of prematurity Sepsis Recurrent respiratory and gastrointestinal infections

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*Source: Reprinted from Home Care of the High Risk Infant by E. Ahmann, p. 3, with permission of Aspen Publishers, Inc. (c) 1986.

INCIDENCE OF PREMATURITY:

Montana	1986	5.7%
	1983	5.5%
National	1983	9.6%

MATERNAL RISK FACTORS:

1. Substance Abuse (alcohol, tobacco, marijuana, cocaine, heroin)
2. Age (less than 17, more than 34 years old)
3. Low socioeconomic status
4. Low educational level
5. Medical risks predating or during pregnancy
6. Poor nutritional status
7. High altitude
8. Infections
9. Inadequate prenatal care
10. History of miscarriage or abortion
11. Previous delivery of a premature infant
12. Multiple gestation (twins, triplets)

SYMPTOMS:

1. Infant's weight usually below 2500 grams. (May be larger due to pathophysiology, such as infant of diabetic mother, or smaller due to intrauterine growth retardation (IUGR)).
2. Infant's gestational age is below 38 weeks by clinical exam.

MEDICAL MANAGEMENT:

1. Monitor and treat any of the problems which arise from prematurity.
2. Support families who give birth to premature infants.

NURSING GOALS:

1. Support family when infant is in NICU at a tertiary care center.
2. Review infant care with parents in anticipation of discharge.
3. Assist families in providing infant's care related to problems arising from prematurity.
4. Encourage families to communicate with health care providers.
5. Assist family in bonding with premature infant.
6. Assist family in meeting unique challenges of health maintenance.

NURSING CARE PLAN - PREMATURE INFANT

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Breast-feeding -- Length of feeding -- Frequency of feeding -- Supplements used -- Feeding system used for supplements (Evenflow, Nuk, Playtex)	Alteration in nutrition: less than body requirements related to immature neurological and digestive systems and increased metabolic demands from increased stress.	Short Term - Parents able to verbalize nutritional needs of infant. Long Term - Parents able to provide adequate nutrition to promote growth and development.	1. Tube feeding. See Appendix at end of chapter. 2. Bottle-fed infant -- If infant has weak sucking reflex use a "preemie" nipple. -- "Preemie" nipples can be found at a hospital pharmacy and some large drug stores.	
Bottle feeding -- Frequency of feeding -- Formula -- Feeding system used -- Source of formula			-- Feedings may be frequent (every 2-3 hours) and often in small amounts at a time (2-4 ounces). -- Bottles should be washed in hot soapy water, rinsed well and dried thoroughly. They don't need to be sterilized if water supply is safe and if infant's immune system is mature and functioning. A dishwasher may be used for bottles, the dishwasher may decrease the life of the nipples.	
Source of iron Supplements (vitamins, etc.) Current medications Birth weight Discharge weight Weight weekly x 12 weeks and then monthly Observation of an infant feeding session -- Parent interaction with infant during feeding			Formula -- Powder - May be mixed with warm tap water (if water supply safe) night before use. Must be refrigerated after mixing. -- Concentrate - Must be refrigerated after opening. May be diluted with warm tap water right before use. (If water supply safe). -- Premixed - Must be refrigerated after opening. -- Do not store formula in refrigerator more than 48 hours.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
-- Duration of feeding			Some premature infants are prone to vomiting after a feeding. To prevent this:	
-- Amount taken				
-- Infant behavior			-- Hold infant so head and stomach are elevated.	
-- Tire easily			-- Burp frequently (after every ½ - 1 oz.)	
-- Fussy before and/or after feed			-- Put pillow between mattress and spring in crib to elevate head. May also use a foam wedge.	
Underlying health problems				
Feeding history (use of total parenteral nutrition, NG tubes, gastrostomy tubes and age of introduction of oral feedings)			-- To keep infant's head elevated, use a sheet which is folded in thirds. Tuck one end under head of bed and fold the other end between infant's legs and pin around under arms.	
History of reflux vomiting				
Method of preparing feeding			-- Lay infant on right side/abdomen for sleep.	
Self feeding skills for older infants			3. Breast-feeding is encouraged for preemies.	
			-- While infant is in hospital:	
Feeding related problems				
			-- Review with parents how to pump breasts.	
Diet record for 1-7 days				
-- Date and time			-- Syntocin nasal spray may help the let-down reflex.	
-- Food/liquid given				
			-- Remind parents that it's normal to only pump 1-3 oz. at a time. Milk supply will increase when baby starts to nurse. As months go by, breast milk production often declines when pumping is done exclusively -- mothers need much encouragement.	
-- Type of preparation				
-- Exact amount in tbsp. and/or ounces				
-- Time and amount of vomiting				

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Tips for pumping: -- Get plenty of rest and relaxation -- Drink 8-10 glasses liquid/day -- Begin pumping A.S.A.P. after delivery (should be within first 24 hours) -- Pump every 2-3 hours for 3 minutes on each side. Increase pumping to 10 minutes on each side. -- Don't need to pump at night unless breasts are full and uncomfortable. -- Massage breasts while pumping to help emptying. -- Think about infant, look at infant's picture, call nursery and ask about infant while pumping. -- Use electric breast pump for most efficient results over long period of time. This can be rented. -- Caring for breast milk after pumping: -- Wash hands, breasts and all equipment to avoid contamination. -- Sterilize pump and/or collection containers as needed and as per manufacturer's instructions. -- Pump and pour milk into a disposable nursery bag. Check with nursery to see how much to put in each bottle.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Label with infant's name, date and time pumped and any other information needed. -- Freeze. Some nurseries allow you to put several layers of milk in same container. Check for sure. -- Storage time - Fresh breast milk - 24 hours in refrigerator. - Frozen in freezer section of refrigerator - 2 weeks. - Frozen at 0 degrees F - 3 months. -- When taking milk to hospital - keep frozen. -- To thaw - Rapid-thaw method is safest. Place container of milk under running tap water (cold to hot) until thawed. Shake well after thawing. Do not allow to sit out on counter for long periods of time to thaw at room temperature. Do not microwave. -- Babies often nurse better at home than in hospital. -- To teach infants to suck: -- DO NOT use honey or corn syrup. -- Stimulate sucking reflex - every baby has a little different way to stimulate sucking. Stroke cheek, rub	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			behind ear, touch around lips, place finger in mouth.	
			-- Stimulate let-down before letting infant nurse.	
			-- Make sure infant has area behind nipple in mouth.	
			-- Change infant's position while nursing, as well as mom's.	
			-- Try Lact-Aid nursing supplementer.	
			-- Use Nuk or Playtex nurser instead of Evenflo to supplement. Use breast milk if possible.	
			-- Be patient, even full-term infants are sometimes difficult to teach to nurse.	
			-- Refer to La Leche League, WIC nutritionist, experienced nursing mother or breast-feeding specialists.	
			-- If infant tires during feeding, try shorter, more frequent feedings.	
			4. Weight on balance beam scale, nude (weekly x 12 and then monthly).	
			-- Post serial weights (include birth weight) on National Center for Health Statistics (NCHS) growth charts.	
			-- Show and explain infant's progress to parents.	
			5. Measure length weekly x 12 and then monthly.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Place infant supine on table/floor. One person holds measuring tape even with the top of infant's head. Another person stretches the tape alongside the infant, while straightening knees and hips, to the base of the heel. -- Plot length on NCHS growth chart. -- Share information with parents. 6. Compare weight for length on NCHS growth chart. -- Weight for length of less than 5% necessitates close nutritional follow-up. A referral to a registered dietitian, where available, may be helpful. 7. Head circumference should be done at least monthly. 8. Common feeding problems in premature infant: Things to do: -- Ineffective sucking: - Make sure infant has all of nipple in mouth. If breast-fed, make sure areola is in mouth. - Use preemie soft single hole (red) nipple.	

Assessment	Nursing Diagnosis	Goals	Plans		Initials Date Completed
				- Enlarge nipple hole with sharp knife.	
				- Allow for frequent rest periods during feeding.	
				- Move nipple up and down in infant's mouth to stimulate sucking movement.	
				- Often, these infants can only deal with one stimulus at a time. Decrease tactile and auditory stimuli during feeding.	
				- Referral to occupational/speech therapist for evaluation, if available.	
			-- Poor coordination of breathing with sucking	- Position neck in neutral midline position.	
				- Promote jaw stabilization to allow free motion of tongue/lips.	
				- Facilitate lip activity by use of pacifier, oral stimulation at times other than	

Assessment	Nursing Diagnosis	Goals	Plans		Initials Date Completed
				feeding, visual and oral feedback by parents of oral and lip movement, and play.	
				- Consistency of persons feeding infant.	
				- Rock infant while feeding.	
				- Minimize activity before and during feeding.	
			-- Neck hyper-extension	- Position infant with head and shoulder elevated above stomach level. If infant is quite small, hold on lap with one hand supporting neck, one hand holding bottle.	
				- Always hold infant during feedings.	
			-- Tactile defensiveness	- Use pacifier	
				- Use different textures of fabrics and touch around mouth first, then lips.	
			-- Lethargy	- Minimize activities before feeding (example: percussion)	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			- Keep infant cool during feeding.	
			- Smaller, more frequent feedings.	
			- Use rocking, gentle bouncing, talking to stimulate infants.	
		-- Food refusal and/or inadequate calorie intake	- Use of higher calorie formula - most usual formulas are 20 cal/oz. Consult with physician and/or nutritionist.	
			- Consult with doctor for formula change.	
			- Calories can be increased in formula by adding calorie supplements:	
			Cal/tbsp. - Polycose 23 - Moducal 30 - MCT oil 115 - Vegetable oil 115	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			- Mix formulas which use oil based calorie supplements in blender or shake well. - Use of butter, margarine, powdered skim milk added to liquids, yogurt, puddings and cereals (after infant has reached the age of 1 year). - Use of cheese and other high calorie foods (after infant has reached the age of 1 year). - Referral to dietician for assistance if available. - Make mealtime pleasant, calm and positive.	
Parental factors which may lead to poor attachment: -- Early life parental deprivations -- Loss of parent figures early in parent's life -- Parents who did not show love	Potential alterations in parenting: attachment related to prolonged hospitalization, family factors, and individual factors.	Parents able to be involved with infant as much as infant's condition and distance etc., allow when infant is hospitalized.	1. Encourage parents to be involved with infant while infant is in hospital. -- Visit NICU as often as possible. If not able to visit, call NICU frequently. -- Give parents positive reinforcement for any type of contact with baby.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
-- Parents who were abusive or neglectful			-- Send pictures of family members to be put where infant can see.	
-- Illness during childhood		Parents able to demonstrate adequate attachment with infant.	-- Always call infant by first name.	
-- Death/illness in prior children			-- Send cassette of one/both parents talking to infant or telling/reading stories.	
-- Emotional/physical illness/death				
-- Unwanted pregnancy			-- Take a picture of baby and keep it in prominent spot in the home.	
-- Cultural expectations that prohibit expression of feelings			-- Send breast milk where possible.	
-- Marital stress			-- May be able to send infant gowns (home-made) for infant to wear.	
-- Substance abuse			-- Send booties for infant to wear.	
-- Financial crisis			-- Send toys for isolette - teddy bear, music box, etc.	
-- Lack of support system				
Infant factors:			-- When parents go to hospital, encourage them to touch, talk to, and provide care for infant.	
-- Abnormal or unexpected appearance				
			2. Assist families with financial problems:	
-- Feeding disorders			-- Encourage parents to make sure hospital billing department has correct insurance information.	
-- Prematurity				
-- Poor weight gain			-- Have parents contact insurance claims department to introduce themselves and explain the situation. Give names of doctors and hospitals involved. Keep records of what you discussed and who you talked to.	
-- Congenital defects				
-- Food refusal				
-- Recurrent vomiting and/or diarrhea				
			-- Organize bills. Keep continuous records of bills and payments.	
-- Developmental delay				

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
-- Sleep disturbance -- Minimal vocalization -- Decreased "cuddliness" Other factors: -- Prolonged separation from infant following birth. -- Procedures or hospital policies which place barriers between infant and parents. -- Hospital staff's failure to incorporate parents into the physical and emotional care of baby prior to discharge. Behaviors in parents which indicate diminished attachment. -- Diminished eye contact between parents and infant -- Limited time when infant and parent are in face-to-face position -- Diminished holding, stroking and touching infant -- Negative descriptions of infant -- Frequent comparisons between infant and a disliked family member.			-- Contact the billing department of each creditor and explain circumstances and manner of payment. Make no promises you can't keep. Contact them about overdue payments before they contact you. -- Pay off small bills first, while making payments on large long-term bills. -- Submit appropriate applications for state assistance (Handicapped Children's Services) 9. Encourage and facilitate communication between spouses. -- Encourage both partners to share feelings and concerns. -- Encourage verbalization of grief. -- Assist parents to divide up tasks to be done. -- Involve both parents in explanations and demonstration. -- Refer for marital or couple counselling if problems become prolonged. 10. Review with parents normal care needs of all infants: -- Bathing and personal care -- Clothing and diapers for premature infants	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
-- Limited positive feedback between parents and infant. -- Diminished verbalization between parent and infant. -- Parents not responsive to infant need. -- Parents do not call infant by name.			-- Immunizations - Check with doctor for recommendations - May need to adjust for prematurity -- Vision and hearing screening as appropriate -- Developmental assessments on routine basis -- Stimulation through touch, sound, change in environment, toys and decorations in baby's visual field. -- Sleep patterns - More frequent wakings to be fed than with with full-term infant - Take longer to sleep through night than full-term infant -- Safety techniques to: -- Prevent falls -- Prevent choking/strangulation -- Prevent burns -- Prevent drowning -- Prevent injuries -- Promote car safety -- Car safety seats - May need to adjust seat straps and provide more cushioning around infant 11. Act as client advocate when infant returns to community -- Be POSITIVE about parents' care efforts	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Assist parents in their efforts to work with health care providers -- Encourage parents to discuss their frustrations when working with the health care system and providers. -- Assist parents in problem-solving in their care efforts with their infants. -- If any questions about infant care, call/write the NICU for clarification. -- Make copy for chart of any instructions sheets sent with infant for care guidelines. Follow instructions with family when possible.	

Note: Premature infants are at risk for developmental delays. Care plans should reflect an active and ongoing assessment for potential problems in neuromotor development and behavior.

RESOURCES

THE PREMATURE INFANT

1. Patterns for premature infant clothing

   -- Parents of Prematures
   Houston Organization for Parent Education, Inc.
   3311 Richmond, Suite 330
   Houston, Texas 77098

   These companies all have catalog mail order:

   -- Anne's Preemie Wear
   c/o Anne Long
   Route 12, Fairview Drive
   Greensville, S.C. 29609

   -- Oh So Small
   Joanne Bock
   6432 Pacific Avenue
   Tacoma, Washington 98408

   -- Tiny Mite Preemie Fashions
   P.O. Box 6346
   Glendale, California 91205

2. Preemie Pampers
   Procter and Gamble 1-800-543-4932

3. Dexter Diaper Factory Dexter B-29 cloth diaper
   236 W. 17th Street
   P.O. Box 7367
   Houston, Texas 77008

4. Preemie Pals Custom Fitted Diapers
   Nancy Nelson
   1313 Harrington Avenue S.E.
   Renton, Washington 98055

5. Breast Feeding

   Hand Pumps

   -- Kaneson Breast Milking/Feeding Unit
   Happy Family Products
   1251 S. LaCienega Boulevard
   Los Angeles, CA 90035

   -- Loyd - B Pump
   LOPUCO
   1615 Old Annapolis Road
   Woodbine, MD 21797

-- Ora-lac Pump
Box 137
Sitka, Alaska 99835

Electric Pumps

-- Egnell, Inc.
412 Park Avenue
Cary, Illinois 60013

-- GOMCO
828 E. Ferry Street
Buffalo, New York 14211

-- Medela, Inc.
P.O. Box 386
Crystal Lake, Illinois 60014

Lactation Counselors

-- Baylor College of Medicine
Lactation Clinic
1200 Moursund
Houston, Texas 77030 (713) 797-0322, 24 hour hot line

-- Lactation Institute
3441 Clairton Place
Encino, CA 91436 (213) 995-1913

-- Breastfeeding Promotion Project
Rita Bradley, R.D.
Pam Garcia, R.N.
RTI, Inc.
630 Utah
P.O. Box 4113
Butte, MT 59702 (406) 782-2386

Premature Infant Support Groups:

Premature Parenthood
c/o Newborn Center
Colorado General Hospital
Box B-195
4200 E. 9th Avenue
Denver, Colorado 80201

Parent-to-Parent
Intermountain Newborn Intensive Care Center (INICC)
University of Utah Medical Center
50 N. Medical Drive
Salt Lake City, Utah 84132 (801) 581-7705

Inland Empire Perinatal Support Group
W. 1622 Fairway Drive (509) 456-8885
Spokane, Washington 99218
(509) 456-8885

Parents of Prematures
c/o Houston Organization for Parent Education, Inc.
3311 Richmond Avenue, Suite 330
Houston, Texas 77098

General Services:

Local County Health Departments

Neonatal Intensive Care Units

-- Missoula Community Medical Center (406) 728-4100
Missoula, Montana

-- Great Falls Deaconess Medical Center (406) 791-5318
Great Falls, Montana

-- Billings Deaconess Medical Center (406) 657-7076
Billings, Montana

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APPENDIX - CHAPTER IV*

Chapter 6

Home Care of the Infant Requiring Tube Feeding

If an infant cannot accept adequate amounts of formula by mouth, the use of tube feeding to provide sufficient intake may be necessary. Inadequate oral intake by the infant may be due to a variety of problems. For example, infants initially maintained on gavage feedings gain little sucking experience in the nursery;[1] such infants commonly have poorly developed orofacial musculature or, because of lack of appropriate desensitizing oral stimulation, hypersensitive oral tissues, leading to ineffective sucking or food refusal. Infants with cardiac or respiratory compromise may not have the strength to suck the amount of formula necessary for adequate growth. Infants with reflux or other disorders causing frequent vomiting may be unable to retain enough formula to satisfy calorie needs.

In these infants, tube feedings can be used to ensure adequate caloric intake. Depending on the nature and severity of the underlying problem, tube feeding may either supplement or replace oral feedings.

TUBE FEEDING OPTIONS

Parents or caregivers who will be involved in the infant's daily care and feeding should participate with the nurse and the physician in deciding upon the most appropriate methods of tube feeding. They should be informed of the options as well as the risks, benefits, and practical details regarding alternative choices. The infant's needs, parental preferences, and safety factors must all be considered in the choice of a home tube-feeding plan.

There are several methods of tube feeding. Gastrostomy tubes are widely accepted for long-term tube feeding. Nasogastric tubes are relied upon for inter-

*Ahmann, Elizabeth, Home Care for the High-Risk Infant. 1986, Aspen Publications, Inc., Rockville, Maryland.

mittent or short-term feeding and are also gaining acceptance for long-term use. Orogastric, nasojejunal, and jejunostomy tubes are used less commonly, and only in special circumstances; they are the least safe for home use. Therefore, only nasogastric and gastrostomy tube feedings are discussed in this chapter.

Nasogastric Tubes

In choosing the appropriate nasogastric (NG) tube for home use, several factors must be considered. First, the size of tube is important. The smaller the lumen of the tube, the more comfortable it is for the child. However, formula passes slowly through a tube with a very small lumen, making feeding times unreasonably long. A lumen size of 8 French is generally adequate for the infant. Second, tubes are made of several types of material; Table 6–1 offers a guide to the advantages and disadvantages of each. Third, it may be helpful to try several tubes to determine the type that the parents are most comfortable inserting. Fourth, if tube feeding is expected to be long-term, the cost of supplies and the likelihood of insurance coverage should be considered in choosing a tube for home use.

Table 6–1 Comparison of Nasogastric Tube Materials

Material	*Cost*	*Reusability*	*Necessity for Stylet or Guidewire*	*Comments and Precautions*
PVC (polyvinyl chloride)	Least expensive	Reusable 1–2 times only; (no more than 48 hours each time)	No	Insertion facilitated if tube is immersed in ice before use
Polyurethane	Mid-range in cost	Yes, long-term	Comes with or without stylet; some have mercury weight to facilitate insertion	May be expelled from stomach with vomiting or strong cough; position must be carefully assessed prior to feeding
Silastic	Most expensive	Not reusable once it has come out	Stylet needed	Same precautions as for polyurethane

Source: Table prepared with assistance of J. Ward, RN, MA, Children's Hospital National Medical Center, Washington, D.C.

Gastrostomy Tubes

Two types of tubes are commonly used for gastrostomy (G) tube feeding: the Malecot self-retaining gastrostomy tube, which has a basket-type end for holding the tube in place, and a Foley catheter, which has a balloon tip that holds the catheter in place. Generally, the size of tube or catheter is chosen by the surgeon who performs the gastrostomy procedure. Nonetheless, it is important for parents to know the tube size since they will need to obtain a replacement if the tube comes out.

FEEDING APPARATUS

NG or G tube feedings can be administered through several types of apparatus. For bolus feeds, a 30- to 60-cc syringe with a regular tip may be inserted into intravenous (IV) extension tubing. The tubing, in turn, is inserted into the NG or G tube. A plastic clamp can be placed on the IV tubing to regulate or stop the flow during feeding.

An alternative to IV tubing is a specially designed feeding set-up. One type consists of a plastic bottle with a cap connected directly to tubing. This set-up can be used if the family is mixing the formula at home. Another type, practical only for use with a feeding pump, is a plastic bag and tubing set that contains premixed formula. This type is generally used for continuous infusion, rather than for bolus feeds.

The frequency and duration of home tube feeding, as well as ease of flow regulation, the size of the drip chamber, and ease of filling with formula, are factors to consider in choosing a feeding apparatus. The choice should also be determined by family preference, convenience, and cost factors.

If a feeding pump is to be used in the home, the community health nurse may be asked to advise on the best choice. Although a variety of pumps are available, not all are sufficiently accurate to allow the precise control necessary to prevent fluid overload in the infant or young child. In some cases, an IV pump may be an appropriate choice. In any event, care must be taken to choose a pump that will permit a slow rate of infusion. Other considerations include the options of a battery mode and of alarms to signal occlusion in the line and empty container, or both.

Ease of operation is another important factor. The supplier or manufacturer of the chosen pump should provide operating instructions for both the family and the nurse. In order to ensure safe and appropriate operation of the pump these instructions should be reviewed with caregivers verbally, by demonstration, and by their return demonstration. Instructions for routine operation of the pump and for responses to alarms should be reviewed. The family should have the opportunity to practice tube feeding in the hospital with the same pump to be used at home.

HOSPITAL DISCHARGE AND TRANSITION TO THE HOME

If an infant is discharged with tube feedings prescribed, it is important to assess the parents' ability to continue the feedings at home. It is important for the community health nurse to be familiar with the hospital's teaching program, the parents' skills and abilities, and any problems or concerns that may have arisen. Optimally, the parents will have demonstrated full responsibility for feeding for a 24-hour period prior to discharge. In addition, at the time of discharge, it is important that the parents have a list of all the supplies needed for the child's feeding, as well as information about where and how to obtain them.

ROUTINE HOME VISITS

On the first and on every subsequent home visit, the infant's growth parameters should be obtained, and both total daily intake and tube feeding intake determined. It is important to note that if tube feedings are needed for supplemental feeding only, intake through the tube may vary daily with the ability to accept oral feeds.

Vomiting, diarrhea, and abdominal cramping may result from *incorrect tube-feeding techniques*. Inquiry about the occurrence of these symptoms should be a part of every home visit. If any of these symptoms is reported, appropriate changes in feeding rate or in formula type, amount, or concentration should be made; suggested interventions are listed in Table 6–2. Such modifications in the feeding plan can be discussed with the infant's dietitian or primary provider.

Skin care is an important part of routine care for the child being tube-fed. If the infant has an NG tube, the nares should be assessed on each nursing home visit. During the visit parents should be able to demonstrate appropriate assessment and care of the nares. Usually, if the tube is taped securely at both the nares and on the cheek, little irritation will occur. Cleansing with a wet cotton swab and changing the tape regularly will also limit the risk of irritation. A tape that ventilates well, such as Micropore tape, may be helpful. Clear surgical adhesive dressings (e.g., Opsite or Tegaderm) have also been used successfully.[2] If the skin does become irritated, the tube should be moved to the other nostril, and the irritated area cleansed carefully. If necessary, an antibiotic ointment can be applied.

If the infant has a G tube, the insertion site should be inspected on each nursing visit. Parents should be able to demonstrate appropriate care and assessment of the G tube site for irritation, rashes, or granuloma formation. Routine care of the area should be accomplished every one to two days. For routine care, the tape is first removed at the G tube site. The area is cleansed with soap and water on a washcloth; soap without a cream or lanolin base will allow the tape to stick better. A cotton swab may be used on and around the tube to remove any crusting. After

Table 6–2 Common Tube Feeding Problems and Interventions

Problem	*Cause(s)*	*Intervention(s)*
Tube site irritation	Movement of tube back and forth	Tape tube securely.
	Skin irritation under tape	Change position of tape every 1–2 days; assess site for infection or granuloma.
Constipation	Inadequate fluid	Increase water.
	Lack of bulk in the diet	Feed prune juice; add sugar to the feeding; feed puréed fruits or vegetables.
	Inactivity	Encourage activity.
Diarrhea	Feeding too fast	Feed more slowly if gravity feeding; check rate with physician if feeding by pump.
	Formula too concentrated in sugar or salt	Consult dietitian or physician.
	Allergy (intolerance) to an ingredient	
	Side effect of medications given with feedings	Divide medications into smaller, more frequent doses if possible.
	Flu or gastroenteritis	Consult physician.
	Feeding formula contaminated by bacteria, or "spoiled" formula	Stress care in daily cleaning of supplies; clean preparations and refrigeration of feedings; and hanging formula for no more than 4–8 hours.
	Lack of bulk in the diet (This does not really cause diarrhea but can make stools so loose as to cause diaper rash.)	Consult with dietitian about adding a bulky food such as puréed vegetables or fruit.
Abdominal cramping IF SEVERE, CALL PHYSICIAN.	Feeding too fast	Slow the rate of bolus feedings; if using a pump, check the rate: if at the prescribed rate, consult with physician about changing rate.
	Feeding too concentrated	Consult with dietitian.
	Gastrostomy allowing air into the stomach	Consult with physician.

Table 6–2 continued

Problem	*Cause(s)*	*Intervention(s)*
Vomiting	Feeding too fast	Feed slower if bolus feeding; consult with physician if feeding by constant drip.
	Feeding tube in the wrong place	Check tube position; tubes in stomach (especially G tubes) may slip out and block the outlet into the intestine.
Aspiration	Tube not inserted fully	STOP FEEDING; CLEAR AIRWAY; call physician. (*Always* check tube placement before feeding.)
	Associated with vomiting	Keep head of bed elevated; position infant on stomach to avoid aspiration.
Plugged tube	Contents not flushed completely through	Prevent by rinsing tube with water after feeding (formula or medications) and before clamping the tube.

Source: Adapted with permission from *Tube Feeding Your Child at Home* by J. Ward, S. Robbins, and L. Riggs, pp. 16–17, Children's Hospital National Medical Center, Clinical Nutrition Group, Washington, D.C., January 1983.

the skin is rinsed and dried thoroughly, it should be inspected carefully. If the skin is intact, the tube can be pulled firmly but gently to assure proper placement. It can then be taped in place. Regularly changing the location of the tape will reduce the risk of irritation. Table 6–3 provides a guide to assessment of possible problems at the G tube site.

THE FIRST HOME VISIT

All aspects of routine visits are, of course, incorporated into the first home visit. In addition, parental preparation to provide safe and appropriate care must be determined. Nurses are further reminded that assessment of the care of the tube-fed infant should be made in conjunction with an evaluation of the infant's nutritional status, including efforts to ensure that nutritional needs are being met. In this connection, a thorough nutritional history should be obtained on the first visit. (Chapter 5 provides a detailed discussion regarding nutrition.)

On the first home visit, assessment of the parents' ability to provide safe and appropriate feeding is important. This is best achieved by observation. If a child

Table 6–3 G Tube Site Care: Possible Problems and Interventions

Problem	*Interventions*
Formula leakage	Check that tube is firmly in place. Cover the area with gauze to protect clothing. Change gauze frequently to prevent maceration of skin. If leakage is heavy, consider placement of larger tube.
Rash or breakdown of skin	Keep area dry; do not apply dressing. Use porous, hypoallergenic tape. Rotate placement of tape daily. For monilial infections, nystatin (e.g., Mycostatin) powder can be dusted on the skin.
Granuloma at G tube site	If small, no intervention is necessary. If problematic, anchor tube over rolled gauze pads to stabilize and reduce irritation at site. Apply silver nitrate carefully.
Tube slips in too far (can cause vomiting or diarrhea)	Check placement of tube regularly with gentle but firm pull. Measure length of tube regularly. Limit risk by anchoring with tape at site and by keeping tube coiled up under clothing.
Tube comes out	Reinsert tube or cover site with gauze and take child to health care provider or emergency facility as soon as possible. Some parents find it helpful to cut off the end of the tube and then insert the tube into the opening. This acts as a stent and keeps the opening the proper size, facilitating reinsertion.

Source: Table prepared with assistance of Liz Riggs, RN, ET, Enterostomal Therapist, Children's Hospital National Medical Center, Washington, D.C.

has an NG tube, the nurse should watch as the parent inserts the tube and *checks its position* prior to a feeding. The position can be checked in two ways: by aspirating for stomach contents and by placing a stethoscope over the infant's stomach and, while quickly injecting 3 cc of air into the NG tube, listening for a popping sound, which indicates correct placement. If not in place, the tube should be removed and repositioned before feeding; a tube placed incorrectly can result in aspiration of formula.

Correct positioning of the infant during tube feedings is important. The infant should be positioned prone, with shoulders higher than feet by at least 30 degrees to facilitate flow of formula through the alimentary tract and to prevent reflux. A sleeping infant can be placed either prone or on the right side, propped by at least 30 degrees. The position should be maintained for 20 to 30 minutes after the feeding.

If the infant is fed by intermittent bolus, feeding should take approximately the same amount of time as for an oral feeding, namely, 20 to 30 minutes. If a pump is not being used, the feeding should run in by gravity. In this case the rapidity of the feeding will be determined by the height of the syringe or bottle. Generally, an appropriate height is 4 inches above the abdomen, although more height may be needed with thicker formulas. The height is important because if the tube is held too high, formula may enter the stomach too fast, causing vomiting, diarrhea, or even overfill with resulting aspiration. If the parent wants both hands free to hold the child, the feeding apparatus can be either hung on a hanger or taped to the wall or crib. Because of the risk of aspiration, it is important that the parent not leave the infant unattended during bolus tube feedings.

If an infant is being fed by continuous infusion, the first visit is an appropriate time to review with parents the instructions for routine operation of the pump and appropriate responses to alarms. The following five principles are important:

1. Positioning, as discussed earlier in this section, will limit the risk of aspiration.
2. To prevent unnecessary infusion of air with the feeding, the drip chamber should be half filled with formula and the entire feeding line completely filled before the tube is attached to the NG or G tube.
3. To prevent spoilage, no more than 4 hours' worth of formula during the day or 8 hours' worth during the night should be hung at one time.[3]
4. Responses to alarms are based on the type of pump; manufacturer instructions should be reviewed with parents.
5. Parents should be within hearing range of the feeding pump alarm; an intercom can be used if the child is in a different room.

The nurse should also assess the parents' confidence in performing the procedures and their comfort in caring for the child during feeding times. It may take time for confidence and comfort to grow, and frequent encouragement during the first several weeks at home can be helpful. During this time, if at all possible, the nurse should be available to visit or to offer phone consultation should any problems arise.

Aspiration is a serious risk with any tube feeding. Steps to prevent aspiration, as well as symptoms and interventions, should be reviewed with parents on the first home visit. During both NG and G tube feedings, appropriate positioning during the feeding (as described previously in this section) is important to prevent aspiration. If at any time during the feeding the child changes color, cannot make noise, or has difficulty in breathing, the feeding should be stopped. With an NG tube, determining proper placement before each feed is also crucial. If the NG tube is accidentally pulled out during the feeding, or if correct placement is uncertain, the parent should reposition the tube before the feeding is resumed and then should remain alert for the signs of aspiration just described. Of course, if aspiration occurs, the physician should be contacted.

SUBSEQUENT VISITS

On each subsequent home visit, it is important to assess the infant's nutritional intake, obtain growth parameters, and, as necessary, observe and review feeding techniques. A history should be obtained about any episodes of vomiting, diarrhea, cramping, or aspiration, and the skin should be assessed for signs of irritation at the nares or at the G tube insertion site. Any parental concerns should also be elicited and addressed. Additional assessment and teaching should address the following issues.

Normalizing the infant's feeding experience, as much as possible, may be important in the prevention of long-term feeding problems. Two aspects of normalization can be reviewed with caregivers. First, in order to assist in maintaining an organized and effective suck and to prevent later oral refusal, caregivers can have the infant suck on a bottle or pacifier during the tube feeding.[4] A pacifier can be used when nutritive sucking is contraindicated or when it is too tiring for the infant. A second aspect of normalizing the feeding experience involves the psychosocial component of feeding. Normal patterns of attachment should be encouraged during each feeding, including holding, cuddling, and talking gently to the infant. (Chapter 5 provides further discussion of the psychosocial component of feeding.)

As a measure to prevent aspiration, checking for *residual stomach contents* prior to a feeding may be important for infants with severe vomiting problems or digestive disorders. As indicated, parents can be instructed in how to check the residual. (It will not be possible, however, to assess accurately stomach residuals when a small-bore NG tube is used.[5]) The nurse should describe and demonstrate the procedure for checking the residual and then watch as caregivers demonstrate the techniques, to assure adequate knowledge.

For checking stomach residuals, the infant should be placed in the supine position. A 20-cc syringe is attached to the end of the tube, and the plunger is pulled; the pull must be gentle to avoid collapsing the tube. Gentle pulling on the plunger is continued until nothing more enters the syringe. The volume of stomach contents in the syringe is called the residual volume; this amount is noted, and then the contents are allowed to flow back into the stomach by gravity. Refeeding the residual prevents loss of fluid and electrolytes. If large volumes of residual remain 1 to 2 hours after a feeding, the next feeding should be delayed. If large-volume residuals persist, a change in formula or in volume of feedings may be indicated.

If medications are given through the feeding tube, or if feedings are intermittent, *clogging of the tube* between feedings may be a problem. Gentle flushing of the tube with several milliliters of water after medications or feedings can prevent this problem. The water should not be forced through the tube; rather, it should be allowed to flow in by gravity. If pressure is necessary to flush the tube, no syringe smaller than 20 cc should be used; smaller syringes exert pressures that can rupture some tubes.[6] If the infant is on a fluid-restricted diet, any water used to flush the tube should be counted as part of the total daily intake. As an alternative method, small amounts of a commercial meat tenderizer (e.g., Accent) dissolved in water or a cola soft drink can be used to clear a clogged tube.[7]

ONGOING CONCERNS

The child's normal daily activities need not be curtailed owing to the use of an NG or G tube. In order to prevent accidental detachment during play, NG or G tubes can be taped securely to the skin or wrapped inside clothing. Other than careful positioning during and after feeding, the infant can be allowed full freedom of movement. The child with a G tube should not be uncomfortable in the prone position, and play in this position should be encouraged. Bathing and tub play are also safe for the infant with the G tube, although parents may need encouragement to be comfortable with this activity.

NOTES

1. Bernbaum JC, Pereira GR, Watkins JB, et al: Nonnutritive sucking during gavage feeding enhances growth and maturation in premature infants, *Pediatrics* 71: 41–45, 1983.
2. Ward J, Children's Hospital National Medical Center, Clinical Nutritional Group, Washington, DC, personal communication, December 1984.
3. Ward J, Robbins S, Riggs L: *Tube Feeding Your Child at Home*, Washington, DC, Children's Hospital National Medical Center, 1983, p 8; Folk CC, Courtney ME: Home tube feedings: general guidelines and specific patient instructions, *Nutr Supp Serv* 2: 19, June 1982. Page and Clibon, on the other hand, suggest that 6 hours is the longest formula should be left hanging at room temperature (Page CP, Clibon V: A method of enterally feeding defined formula diet, *Am J Intrav Ther Clin Nutr*, January 1982, p 29.
4. In a study of premature infants, at a mean age of 10 days, nonnutritive sucking was found to accelerate the maturation of the sucking reflex, decrease intestinal transit time, and cause a more rapid weight gain (see Bernbaum JC: Nonnutritive sucking.)
5. Rogers L, Moss JP, Wright RA: New developments in enteral feeding techniques, *Nutr Supp Serv* 2: 19, October 1982.
6. Folk CC, Courtney ME: Home tube feedings, p 19.
7. Ward J: personal communication, December 1984.

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V. THE INFANT WITH PROBLEMS OF CHEMICAL REGULATORY MECHANISMS

CONGENITAL HYPOTHYROIDISM

DEFINITION:

Congenital hypothyroidism may be caused by either failure of the embryonic development of the thyroid gland or inborn defects in the synthesis of thyroxine.

PATHOPHYSIOLOGY:

The thyroid gland is absent or the tissue is insufficient to produce adequate amounts of thyroxine.

INCIDENCE:

One of the most common endocrine dysfunctions in childhood. One in 3500-4500 live births.

RISK FACTORS:

A. Female
B. Family history
C. Prematurity

TYPES:

A. Cretinism
B. Hashimoto's Thyroiditis -- Autoimmune process causing damage to the thyroid.

ONSET:

3-6 months of age in bottle-fed infants
Following weaning in breast-fed infants

SYMPTOMS:

A. Before 3-6 months of age:

    Prolonged physiologic jaundice
    Feeding difficulties
    Inactivity (excessive sleeping and minimal crying)
    Anemia
    Hypotonic muscle tone

B. After 3 months of age:

    Mental retardation
    Slow awkward movements

Lethargy
Sleepiness
Slow deep tendon reflexes
Short stature and obesity
Delayed teething with defective teeth coming in
Yellowish skin
Cold intolerance
Anemia
Decreased pulse, circulation and pulse pressure
Dyspnea and decreased respiratory effort

MEDICAL MANAGEMENT:

A. Indefinite thyroid replacement therapy
B. Regular evaluation of thyroid and triiodo-thyronine levels
B. Bone age surveys

NURSING GOALS:

A. Teach parents about the disease and the care of the infant with hypothyroidism.

B. Assist parents in working through their feelings about this child.

C. Assist parents in promoting optimum development in their infant.

DIABETES INSIPIDUS

DEFINITION

Hyposecretion of antidiuretic hormone by the posterior pituitary gland.

PATHOPHYSIOLOGY

Without antidiuretic hormone, the regulation of the kidney's excretion of water is not controlled. The infant excretes large amounts of water.

INCIDENCE: UNKNOWN

RISK FACTORS

A. Family history

TYPES

A. Primary diabetes insipidus: Genetically transmitted or idiopathic causes.

B. Secondary diabetes insipidus: Damage to the posterior pituitary gland.

C. Nephrogenic diabetes insipidus: Unresponsiveness of the renal tubules to antidiuretic hormone. (Very rare)

ONSET

Any time after birth.

SYMPTOMS

A. Irritability that is relieved by feedings of water but not milk.

B. Dehydration (sunken fontanels, dry cracked lips, dry, flaky skin, sticky mucous membranes, soft eyeball tension, sunken eyes).

C. Electrolyte imbalance.

D. Fever.

E. Presence of nitrogen in urine.

MEDICAL MANAGEMENT:

A. Control of symptoms through IM or Sub Q injection or nasal spray of vasopressin.

NURSING GOALS

A. To teach parents the proper administration of vasopressin.

B. To assist parents in differentiating between diabetes insipidus and diabetes mellitus.

C. To assist parents in working through feelings and bonding with this child.

NURSING CARE PLAN - CONGENITAL HYPOTHYROIDISM

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Prolonged physiologic jaundice Feeding difficulties Excessive sleeping and minimal crying Poor weight gain Hypotonic muscle tone Anemia Lethargy Slow, deep tendon reflexes Delayed teething Dry/coarse skin Yellowish skin Decreased pulse and pulse pressure Dyspnea and decreased respiratory effort Constipation Hoarse cry	Alteration in nutrition: chemical imbalance related to inadequate production of thyroxine.	Parents are able to explain importance of giving medication Parents demonstrate medication administration safely.	1. Explain to parents what Thyroxine does: -- Regulates metabolic rate -- Controls rate of growth of body cells -- Especially important for growth of bones, teeth and brain -- Promotes the body's use of fats and the use of glycogen 2. Have parents demonstrate how they give the medications. 3. Review side effects of thyroid medications -- Staring expression in eyes -- Cardiac arrhythmias -- Palpitation -- Weight loss -- Tremors -- Fever -- Diarrhea -- Warm moist skin 4. Check for symptoms of overdose - most likely to occur 1-3 weeks after therapy is begun. 5. Physical examination monthly and PBI levels every three months. 6. Teach parents to take sleeping apical pulse and basal morning temperatures. 7. Give medication before morning feeding. 8. Explain that they will see rapid change in infant (increased hair loss, increased assertiveness in previously passive infant, initial rapid weight loss and rapid catch up of growth). Symptoms usually disappear with continued therapy.	

NURSING CARE PLAN - CONGENITAL HYPOTHYROIDISM

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			9. Monthly height and weight. Watch for rapid height gain.	
			10. Count apical pulse before each dose and during period of dose adjustment. Notify M.D. if apical pulse above 160.	
			11. Notify M.D. if diarrhea present.	
			12. Teach parents to avoid ingestion or exposure to iodine preparations.	
			13. Encourage family to discuss their feelings and concerns.	
			14. Developmental testing using D.D.S.T., Washington Guide or Portage Guide. If developmental delays found, refer to Care Plan: Developmental Disabilities	

NURSING CARE PLAN - DIABETES INSIPIDUS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Irritability that is relieved by water feeding, not milk feedings. Polyuria Hyperthermia (fever) Rapid weight loss Vomiting Constipation Growth failure Dry, pale skin Dry, sticky oral mucous membranes Sunken fontanels Inelastic skin turgor Sunken, soft eyeball tension Crying without tears Persistent diaper rash Irritable to lethargic	Fluid volume deficit related to insufficient amounts of antidiuretic hormone.	Parents are able to demonstrate administration of medication. Parents are able to explain the importance of adequate fluid intake and the amount of fluids their child needs.	1. Review with parents the procedure for injecting the vasopressin. -- Hold vial of vasopressin under warm, running water for seven (7) minutes. -- Shake vial vigorously for (1) one minute. -- Draw vasopressin into a syringe with a 21-23 gauge, 1 inch needle. -- Inject into the large muscle in the anterior thigh. (Deep I.M.) Stress landmarks for locating vastus lateralis muscle. Identify greater trochanter and knee. Injection site is in the middle third of the distance between these two landmarks, on the lateral aspect of the thigh. Use only 3/4 inch to 1 inch needle for injection. -- Give medication with 8 oz. bottle water -- The effects of the injection lasts 48-72 hours. -- Blood pressure and weight weekly. Notify doctor of sudden changes. -- Remind parents to alternate thigh sites but they cannot use the deltoid or dorsogluteal sites in infants. -- Shorter-acting nasal spray vasopressin is available for older children.	

NURSING CARE PLAN - DIABETES INSIPIDUS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			2. Review with parents the signs of dehydration and make sure the parents know how to assess for dehydration. -- Sunken fontanels -- Rapid weight loss -- Dry, pale skin and lips -- Dry, sticky oral mucous membranes -- Inelastic skin turgor over abdomen	
			3. Review with parents signs of over hydration -- Bulging fontanel -- Rapid weight gain -- Puffy eyelids -- Dilute, very pale urine -- Sunken, soft eyeball tension -- Crying without tears in the infant who normally has tears	
			4. Parents to weigh child daily -- Nude -- At the same time every day -- Diapers should be weighed after voiding. Accurate daily output should be recorded.	
			5. Make sure parents know how much fluid the infant must have minimally in order to maintain hydration. 10 days of age 80-100 ml/kg/24° 3 months 140-160 ml/kg/24° 6 months 130-135 ml/kg/24° 9 months 125-145 ml/kg/24° 12 months 120-135 ml/kg/24°	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			2.2 Kg = 1 pound Convert measurements to ounces, cups and tablespoons for parents. 30 cc (ml) = 1 oz. 6. After six months of age, offer infants other fluids in addition to formula. Other fluids might include apple juice, 1/2 strength gator aid, flat 7-up, popsicles, cranberry juice. 7. Review with parents procedures for administering electrolyte supplements if ordered. 8. Dress infant in cool clothing during times of high heat. 9. Avoid high activity levels in infant during hottest parts of the day. 10. Notify physician of any illness (especially one that has fever, vomiting and/or diarrhea) immediately. 11. Increase fluid intake during periods of fullness. 12. Maintain a record of how many diapers/24°. 13. For persistent diaper rash: -- Keep infant dry as much as possible. -- Avoid use of plastic pants. -- If using cloth diapers, be sure all detergent is rinsed out. -- Use disposable "diaper daubers" as liners - these have some wicking action as disposable diapers.	

NURSING CARE PLAN - DIABETES INSIPIDUS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Expose infant's bottom to air 15 minutes twice a day. -- Bathe in warm water daily. -- If using disposable diapers, change frequently. -- Hydrocortisone cream for persistent rash. * Families may need financial aid for diapers because of large urinary output. If family has a washer and dryer, cloth diapers may be more economical. 14. Infant should wear Medic-Alert bracelet.	

RESOURCES

THE INFANT WITH PROBLEMS OF CHEMICAL REGULATORY MECHANISMS

1. Shodair Lay Lending Library
   Medical Genetics Library (406) 442-1980
   840 Helena Avenue
   Helena, MT 59601

2. Health Information Clearinghouse
   P. O. Box 1133 1-800-336-4797
   Washington, D.C. 20013

3. Montana Department of Health and
   Environmental Sciences
   Health Services Division (406) 444-4740
   Cogswell Building
   Helena, MT 59620

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5. Whaley, L.J. and Wong, D.L.: Nursing care of infants and children. St. Louis, 1983, C.V. Mosby Company.

VI. THE INFANT WITH PROBLEMS OF NEUROLOGICAL REGULATORY MECHANISMS

TAY-SACHS DISEASE (AMAUROTIC FAMILIAL IDIOCY)

Definition: Autosomal recessive single-gene disorder

Pathophysiology: Body doesn't manufacture hexosaminidase, an enzyme necessary for the synthesis of gangliosides. This inhibits function of the peripheral and central nervous system.

Incidence: 1 in 25 in Ashkenazi Jews.

Risk factors:

1. Ashkenazi Jews.

Onset: 4-6 months of age with death occurring by 3-4 years of age.

Symptoms:

1. Psychomotor retardation
2. Deterioration after 4-6 months of age of normal development
3. Hypotonia
4. Lethargy and apathy
5. Poor head control
6. Cherry red spot in the macula
7. Seizures
8. Enlarged head

Medical Management:

1. Care for recurrent infections
2. Parental support

Nursing Goals:

1. Support parents through grief process
2. Teach parents prevention and care intervention for infections
3. Teach parents about and provide resources for managing special care needs of child: feeding, personal hygiene, maintenance of maximum mobility, etc.

For care plan, see Infant with Potentially Terminal Illness and Infant with Developmental Disabilities.

DEFECTS OF NEURAL TUBE CLOSURE (SPINA BIFIDA)

Definition: Defective development of any part of the spinal cord

Pathophysiology:

1. The neural tube fails to close by the end of the fourth week of gestation

   or

2. A splitting of a portion of the already closed neural tube probably caused by an abnormal increase in cerebrospinal fluid during the first trimester

Incidence: .2 - 4.2 per 1,000 live births

Risk factors:

1. Family history of spina bifida and/or anencephaly
2. Maternal viral infection in first trimester
3. Exposure to radiation during first trimester
4. Exposure to environmental pollutants during first trimester

Types:

1. Spina bifida occulta - Fusion failure of posterior vertebral arches without herniation of the meninges or spinal cord. Associated with no neurological deficit. As many as 24% of all children have such a bony defect.

2. Meningocele - A sac-like cyst made up of meninges and filled with spinal fluid which protrudes through a defect in the bony spine.

3. Myelomeningocele (meningomyelocele) - A sac-like cyst made up of meninges, spinal fluid, spinal cord and its nerves which protrudes through a defect in the bony spine.

Onset: Birth through 18 months of age.

Symptoms: Depend on the level of spinal cord in which the lesion occurs, but most common level of occurrence is lumbar or lumbosacral area. Below second lumbar vertebra:

- Sensory impairment
- Bladder overflow incontinence and constant dribbling of urine
- Lack of bowel control
- Rectal prolapse
- Flexion and/or extension contractures
- Kyphosis
- Lumbosacral scoliosis
- Hip disolations
- Hydrocephalus

Medical Management:

1. Surgical correction of spina bifida
2. Surgical shunting of hydrocephalus
3. Orthopedic correction of musculoskeletal problems
4. Management of bowel and bladder problems

Nursing Goals:

1. Teach parents prevention interventions for bladder infections, skin breakdown and limb deformities
2. Provide anticipatory guidance in the areas of attachment, nutrition and growth and development
3. Assist families in facilitating developmental progress
4. Refer family for genetic counselling
5. Coordinate support services to families
6. If infant is terminal, assist family member's grief work
7. Teach parents colostomy, bladder and skin care

HYDROCEPHALUS

Definition: Excessive accumulation of cerebrospinal fluid (CSF) under increased pressure.

Pathophysiology: Under the increased pressure of C.S.F., the ventricles become dilated and the brain substance is compressed against the bony cranium. This inhibits brain growth and activity. The head becomes larger and larger in response to the increased CSF in the cranium.

Incidence: 1-4 per 1,000 live births

Risk factors:

1. Developmental malformations
2. Neoplasms
3. Infections (prenatal and neonatal)
4. Trauma

Types:

1. Excess secretion: Overproduction of cerebrospinal fluid
2. Intraventricular: Blockage within the ventricular system
3. Extraventricular: C.S.F. is not absorbed from the cerebral subarachnoid space

Onset: May appear at anytime from fetal life to early adulthood

Symptoms:

1. Abnormally large infant head circumference or rapidly increasing head circumference
2. Bulging fontanels
3. Palpable suture lines
4. Dilated scalp veins especially during crying
5. Frontal enlargement and depressed eyes
6. Irritability
7. Lower extremity spasticity
8. Difficulty in sucking and feeding
9. Shrill, brief high-pitched cry
10. Setting-sun sign (sclera becomes visible above the iris as increased pressure alters positioning of eyes)

Medical Management:

1. Surgical treatment

    - -- Correction of C.S.F. obstruction
    - -- Reduction of C.S.F. production
    - -- Ventricular bypass into a normal intracranial channel
    - -- Ventricular bypass into an extracranial compartment (peritoneal cavity, right atrium of heart)

Nursing Goals:

1. Teach parents about hydrocephalus
2. Teach parents care of shunt after surgery
3. Support parents emotionally
4. Assist parents in promoting optimum development.

SEIZURES

DEFINITION:

A sudden involuntary muscle contraction and relaxation.

PATHOPHYSIOLOGY:

Electrical discharges which:

1. May begin in a localized portion of cortex and spread to other portions of brain.

2. May begin in portion of brain which controls consciousness.

3. May be restricted to one portion of cortex and remain in that portion of the cortex.

INCIDENCE:

It has been estimated that 4 percent of all children experience a small amount of seizure activity between infancy and childhood; that 1 percent of newborns will exhibit seizure actvitiy; and that 25 percent of prematures in an NICU will exhibit seizure activity.

RISK FACTORS:

1. Idiopathic epilepsy
2. Trauma
3. Anoxia
4. Intracranial infection
5. Drug withdrawal
6. Hypoglycemia
7. Uremia
8. Developmental anomalies

ONSET:

Anytime after birth.

SYMPTOMS: (It is difficult to recognize a seizure in an infant because of the immaturity of the nervous sytem.)

1. Repetitive, stereotypic, nonspecific movement that is not stimulus-sensitive.

2. Eye movement and pupil dilation.

3. Muscle contractions.

4. Loss of consciousness, apnea, or cyanosis.

MEDICAL MANAGEMENT:

1. Control of seizure activity through medications.
2. Dietary control of seizures.
3. Surgical therapy.

NURSING GOALS:

1. Ascertain parents' level of knowledge regarding seizure activity, and to teach accordingly.
2. Review with parents measures used to control seizure activity.
3. Provide emotional support to family as they deal with unpredictability of seizure disorder and the effect it has on their lives.

NURSING CARE PLAN - NEUROLOGICAL ABNORMALITIES

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Family history of neural tube closure problems.	Impaired physical mobility related to impaired and/or absent neurological stimulation to muscles.	Parents are able to discuss the importance of mobility to development.	1. Referral to physical therapist and/or occupational therapist for care plan development.	
Birth history -- Length of labor -- Periods of fetal heart tones of below 120 beats per minute -- Presentation of fetus at birth -- Use of medications type, dosage and length of time used -- Prematurity -- Small for gestational age -- Exposure during pregnancy to x-ray, drugs, communicable disease		Parents are able to demonstrate skills necessary to encourage motor development.	2. Test developmental level using Portage Guide or Washington Guide to Development (found in Whaley and Wong, Nursing Care of Infants and Children). Testing should be repeated every two months in first year of life. 3. Assess home environment for levels of developmental stimulation using Home Observation for Measurement of the Environment (H.O.M.E.) by Bettye M. Caldwell, 1979. Copies may be found in Whaley and Wong's Nursing Care of Infants and Children. 4. Review with parents how to do range of motion. -- R.O.M. should be done every two hours while awake	
Motor function Strong Weak Spastic Right arm Left arm Right leg Left leg			-- Support the joints when doing R.O.M. -- Firm, steady pressure is best when working with spastic muscles, when doing R.O.M. -- Each joint should be taken through its full R.O.M.	
Range of motion all joints (describe in degrees the R.O.M. of each impaired joint)			5. Reposition the infant every two hours. -- Review good body alignment -- Use sandbags, towel rolls, and pillows to maintain good body alignment	

NURSING CARE PLAN - NEUROLOGICAL ABNORMALITIES

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Intracranial pressure			-- Change location of infant frequently (where family members go, infant should follow)	
-- Previous symptoms of increased intracranial pressure				
-- Fontanels			6. Promote muscle tone by encouraging infant to develop muscle strength and tone.	
-- Location & type of shunt			-- Play games with infant which have infants pull/push/reach for objects	
-- A record of serial head circumference measurements			-- Use Portage Guide activity cards to give parents ideas about activities which promote muscle strength and tone	
Developmentally appropriate self care skills				
-- Ability to roll over			7. Provide infant a method of mobility by six months of age (Creeper [may be found in mechanic section of variety stores], infant walker).	
-- Ability to sit by self				
-- Ability to crawl/creep/or otherwise get around			8. Assist parents in identifying safety hazards in the home.	
-- Ability to pull self to standing			9. If infant has a shunt for hydrocephalus, review with parents disease process, and care and checking of shunt.	
-- Ability to take a few steps by self				
-- Use of assistive devices			10. Teach parents to check for symptoms of shunt obstruction	
-- Wheelchairs -- Crutches -- Braces -- Walker (infant)			-- Tense, bulging fontanel -- Increased head circumference -- Vomiting -- Change in appetite -- Irritability -- Increased sleepiness -- "Sunset" eyes	
-- Restrictive devices				
-- Casts -- Splints -- Braces				

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Level of stimulation provided by family members to infant			11. As infant approaches one year, review with parents expectations for infant behavior and plans for discipline methods.	
Motivation of family to follow through on intervention (as perceived by nurse and as stated by family)			12. Remind parents to assess skin for breakdown especially at pressure points under casts, braces and splints.	
On each home visit assess:			13. Review with parents appropriate body alignment.	
-- Level of orientation -- Alertness -- Head circumference -- Fontanels -- Suture Lines -- Shunt Insertion site -- Eye Movements			14. Assess monthly feeding routine, problems and height and weight.	

NURSING CARE PLAN - SEIZURES

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Parental understanding of infant during seizure activity. Safety of home environment. Knowledge of family members re: storage and administration of seizure control medications. Information from hospital: -- type of seizures -- how the seizure manifests -- infant's behavior after seizures -- prescribed medications -- reaction to prescribed medications	Potential for injury related to seizure activity.	Family able to identify safety hazards in environment and develop preventive measures. Family able to describe seizure disorder and demonstrate proper care.	1. Review with family members safety precautions for infants (even more important for infants with seizure disorders). -- No pillows in crib -- Crib mattress should fit snugly against sides of crib -- Crib slat openings of no more than 2-3/8 inches -- No plastic bags around infants -- Never have infant on bed, table, counter, etc., unattended -- Don't tie a pacifier on a string around infant's neck -- Don't leave infant alone in bath even for a short period of time -- Never put infant to bed with a bottle -- Make sure medications are kept in a LOCKED container (do not trust child-proof bottle caps) -- Toys should be labeled non-toxic and have no small and/or removable parts -- Sharp corners on furniture at infant's level should have corner protectors -- When infant begins to move by self -- Safety latches on cupboard doors which have harmful substances and/or objects	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Gates at bottom and tops of stairways	
			-- Be sure doors are closed and latched	
			-- Small objects picked up off floors	
			-- Adult supervision when infants are outdoors	
			-- If seizures are frequent, use of helmet when infant begins standing and walking	
			2. Review with all adult family members care of the infant during a seizure.	
			-- Monitor time and length of seizure	
			-- Place infant in safe place, where he can't bump against any objects during the seizure	
			-- DO NOT place anything in the infant's mouth	
			-- When seizure is over, place infant on his side with head slightly elevated	
			-- Record seizure in seizure diary	
			-- Length of seizure	
			-- Incidents preceding seizure	
			-- Eye movement and pupil size	
			-- Muscle movement during seizure	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Loss of consciousness -- Behavior of infant following seizure -- Encourage infant to resume normal activities as soon as infant wants to -- Review with parents when to seek medical assistance 3. Review, with parents, the administration of seizure control medications -- Store all medications in LOCKED container out of reach of children -- For infants with several medications, be sure parents understand which medication should be given at which time -- Assist parents in planning medication administration times which minimize waking infant during periods of sleep -- Review with parents, prevention and treatments for side effects of various medications -- Epilepsy Foundation of America has discount pharmacy service - write for more information 4. Encourage parents and other family members to discuss their questions and concerns about seizure disorders with each other and with health care providers.	

NURSING CARE PLAN - SEIZURES

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			5. Some common myths about seizure disorders. -- Punishment from God -- Possessed by devil/evil -- Everyone with seizures is retarded -- People with seizures can't drive cars, go to college, get married, hold jobs, etc. -- People with seizures shouldn't exercise or be involved in sports -- People who have seizures may swallow their tongues 6. Get Medic Alert bracelet for infant. 7. Prevent infections in infant.	

RESOURCES

THE INFANT WITH PROBLEMS OF NEUROLOGICAL REGULATORY MECHANISMS

1. Epilepsy Foundation of America
1828 "L" Street, N.W.
Washington, D.C. 20036
Has discount pharmacy service

2. National Easter Seal Society (312) 243-8400
2023 W. Ogden Avenue
Chicago, Illinois 60612

3. Spina Bifida Association of America (312) 663-1562
343 S. Dearborn #319
Chicago, Illinois 60604

4. United Cerebral Palsy Association (212) 481-6300
66 East 34th Street
New York, New York 10016

5. National Tay-Sachs and Allied Disease Assn. (212) 661-2780
122 E. 42nd Street
New York, New York 10017

6. Developmental Disabilities Division (406) 444-2490
Department of Social and Rehabilitation Serv.
111 N. Sanders
Helena, Montana 59601

7. Child and Family Services

A. Region II Child and Family Services (406) 452-9531
1500 9th Avenue South
Great Falls, Montana 59405

B. Family Outreach, Inc. (406) 443-7370
825 Helena Avenue
Helena, Montana 59601

C. Developmental/Educational
Assistance Program (406) 232-6034
Box 989
Miles City, Montana 59301

D. Developmental Assessment Services (406) 365-6031
East Little Street
Glendive, Montana 59330

E. Hi Line Home Programs (406) 228-9431
P.O. Box 469
Glasgow, Montana 59230

8. Epilepsy Association

A. Copper Chapter (406) 452-9323
600 Northwest Plaza
Great Falls, Montana 59401

B. Dillon Chapter (406) 683-5030
305 Nelson
Dillon, Montana 59725

C. South West Montana (406) 723-4243
c/o Denise Kagie
405 West Park
Butte, Montana 59701

9. Helena Cerebral Palsy Group
Judy Gardner
1430 Brady
Helena, Montana 59601

10. Montana Center for Handicapped Children (406) 657-2312
Normal Avenue and Poly Drive
Billings, Montana 59601

11. Montana Coalition of Handicapped (406) 549-7074
P.O. Box 4374
Missoula, Montana 59806

12. Montana Easter Seal Society/
Goodwill Industries (406) 761-3680
4400 Central Avenue
Great Falls, Montana 59401

Bozeman	994-4563
Butte	782-0327
Billings	252-9600
Conrad	278-7558
Havre	265-6151
Helena	442-2061

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VII. THE INFANT WITH PROBLEMS OF SENSORY REGULATORY MECHANISMS

STRABISMUS

DEFINITION:

Inability to fixate with both eyes on one visual field.

PATHOPHYSIOLOGY:

By 3-4 months, the infant develops the ability to use both eyes to look at one visual field. Non-development may be caused by poor innervation to one or more eye muscles, by muscular dysfunction or by detached tendons. Correcting strabismus preserves vision, binocularity, and improves appearance.

INCIDENCE:

Unknown

RISK FACTORS:

1. Family history

TYPES:

1. Accommodative strabismus - Distance vision is normal but close vision is disrupted and deviation of the weak eye occurs.

2. Nonaccommodative esodeviation - Distance vision is also involved.

ONSET:

Any time after 4 months of age.

SYMPTOMS:

1. Malalignment of eyes for near and/or distance vision.
2. Squinting.

MEDICAL MANAGEMENT:

1. Correction through use of:

    -- Covering/patching the strong eye.
    -- Corrective lenses.
    -- Anticholinesterase agents to reduce accomodation.
    -- Orthopedic exercises.

NURSING GOALS:

1. Early identification.
2. Referral.
3. Encouragement of family to follow through on treatment.

RETROLENTAL FIBROPLASIA (R.L.F.)

DEFINITION:

Blindness related to oxygen therapy, primarily in premature infants.

PATHOPHYSIOLOGY:

1. Vasoconstriction of retinal capillaries caused by high concentration of oxygen.

2. Wild overgrowth of these developing blood vessels occurs.

3. The humor becomes turbid from large numbers of blood vessels.

4. Retina becomes edematous and detaches.

5. Scarring occurs causing irreversible blindness.

INCIDENCE:

Unknown.

RISK FACTORS:

1. Prematurity.

2. Prolonged exposure to oxygen concentrations.

ONSET:

Following use of oxygen.

SYMPTOMS:

1. On opthalmalogic exam:

    a. Abrupt termination of retinal vessels.
    b. Peripheral retina pale and gray.
    c. Retinal hemorrhages.
    d. Retinal detachment.

2. Neovascular membrane seen in the vitrious.

3. Secondary angle glaucoma in a blind, painful eye.

4. Myopia.

MEDICAL MANAGEMENT:

1. Prevention through careful monitoring of oxygen levels and arterial oxygen tension in premature neonates.
2. Early identification and referral of R.L.F.

NURSING GOALS:

1. Support of parents during diagnosis.
2. Promotion of parental-infant attachment with a vision impaired infant.
3. Assist families in developing altered communication styles which aren't dependent on visual cues.
4. Promotion of development during first year of life.
5. Assist family to identify safety hazards for infant who is vision impaired.

RETINOBLASTOMA

DEFINITION:

Congenital malignant tumor developing in the retina.

PATHOPHYSIOLOGY:

1. Tumor (malignant) which develops on retina.
2. May invade other portion of eye, brain, bone, lymphatic system, and/or liver.

INCIDENCE:

1 in 14,000-34,000 live births.

RISK FACTORS:

1. Family history of retinoblastoma.
2. Exposure to radiation during pregnancy.

ONSET:

Anytime after birth.

SYMPTOMS:

1. Cat's eye reflex - white glow as light hits tumor.
2. Strabismus.
3. Blindness.
4. Red, painful eye.
5. Glaucoma.

MEDICAL MANAGEMENT:

1. Tumor reduction.
    -- Radiation
    -- Lasar
    -- Cryosurgery with Chemotherapy
2. Referral for genetic counselling.

NURSING GOALS:

1. Support of family during diagnosis and treatment.
2. Support of family during grief response to blindness.
3. Review with parents the care, insertion and removal of prosthesis.
4. Follow up on genetic counselling.
5. Assist family in developing altered communication styles with visually-impaired infant.
6. Assist family in providing an environment free of safety hazards for visually-impaired infant.

HEARING LOSS

DEFINITION:

Inability to hear and respond to sounds greater than 30 decibels.

PATHOPHYSIOLOGY:

Absence/damage to any structure of the external, middle or inner ear.

INCIDENCE:

1 in 600-800 normal neonates and 1 in 60 neonates in intensive care.

RISK FACTORS:

1. Prenatal risk factors.

   a. Maternal anoxia.
   b. Alcoholism.
   c. Diabetes.
   d. Drugs (esp. quinine, aspirin, mycin antibiotics).
   e. Preeclampsia/eclampsia.
   f. Perinatal infection such as toxoplasmosis, herpes, rubella, cytomegalovirus and syphilis.

2. Perinatal risk factors.

   a. Severe asphyxia (Apgar 0-3)
   b. Bilirubin levels that required treatment
   c. Birthweight less than 150 mg.
   d. Prolonged labor and delivery.

3. Postnatal risk.

   a. Frequent ear infections.
   b. Exposure to loud and/or continuous noise (loud music, isolette, NICU noises).
   c. Infections (measles, mumps, rubella, Meningitis, encephalitis).
   d. Exposure to mycin antibiotics.
   e. Trauma.

4. Family/genetic factors.

   a. Cerebral palsy.
   b. Chromosomal abnormalities.
   c. Anatomic malformation of head and neck.
   d. Connective tissue disorders.
   e. Family history of congenital deafness.
   f. Mental retardation.
   g. Pigment abnormalities.
   h. Retinitis pigmentosa.
   i. Skeletal defects.
   j. Visual handicaps.

TYPES:

1. Conductive loss - Interference of sound transmission to the middle ear.

2. Sensoneural loss - Inability of the inner ear and/or auditory nerve to transmit sound.

3. Mixed conductive - sensoneural loss - Damage to both middle ear structures and neural pathways.

4. Central auditory imperception - All other hearing losses for which there is no demonstrable damage to ear or neural structures.

ONSET:

Anytime after birth.

SYMPTOMS:

1. No reaction to sound.
2. Persistence of Moro reflex after 4 months of age.
3. No turning of head/eyes to sound source.
4. No babbling/voice inflection by 7 months of age.
5. Inability to understand words/sounds by 12 months of age.
6. Persistent/frequent ear infections.

MEDICAL MANAGEMENT:

1. Prevention.
2. Early identification.
3. Surgical correction of structural defects where possible.
4. Aggressive treatment of ear infections.

NURSING GOALS:

1. Prevention and early identification.
2. Support family in efforts to cope with feelings.
3. Teach family about hearing loss.
4. Teach family care of hearing impaired infant.
5. Assist family in bonding with hearing impaired infant.

NURSING CARE PLAN - VISUALLY IMPAIRED INFANT

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Doesn't focus or follow objects No orientation to visual stimuli Doesn't initiate eye-to-eye contact with caregiver Squints/frowns Inaccurate judgement in picking up objects Tilts head to one side Constant nystagmus Fixed pupils Marked strabismus Cross-eye Redness Excessive tearing Corneal haziness Gray opacities of lens Corneal light reflex - Shine into eyes at a distance of 16". If eyes are normal, light falls symmetrically in pupils of both eyes. Not normal, light falls off center in deviated eye.	Sensory-Perceptual alteration related to impaired/loss vision.	Parents are able to discuss their questions/concerns about having a vision impaired infant. Parents are able to demonstrate attachment behaviors which aren't dependent on visual awareness. Parents able to demonstrate behaviors which will stimulate development in the vision impaired infant.	1. Refer family to: Montana School for Deaf & Blind 3911 Central Avenue 453-1401 Great Falls, MT 59401 2. Encourage parents to express fears, concerns, questions, feelings of grief. 3. Assist parents in setting realistic goals for infant. 4. Stress infant's abilities rather than disabilities. 5. Discuss importance of discipline and limit setting. 6. Assist families in identifying safety hazards as infant becomes mobile. 7. Help parents and family to identify cues other than eye contact that their infant is listening (infant becomes attentive at sound of mother's voice, moves in synchrony with rhythm of voice, etc.). 8. Encourage parents to discuss their concerns about lack of visual contact or smiling from infant. Explain that lack of above doesn't mean dislike. 9. Have parents take infant's hands and trace touch parents face when parents talk to infant.	

NURSING CARE PLAN - VISUALLY IMPAIRED INFANT

Assessment	Nursing Diagnosis	Coals	Plans	Initials Date Completed
Cover test - Cover one eye and observe the movement of uncovered eye while infant looks at near and distance objects. If uncovered eye moves, deviation is present.			11. Encourage family members to talk to infant as much as possible, and to pick up cues that infant is recognizing individual voices.	
			12. Once infant has "discovered" hands, use hands to explore other body parts. Parents can make infant aware of other body parts by blowing/patting feet, tummy. Then guide infant's hands over his/her body.	
			13. Lift infant up in air and slowly and gently move through air.	
			14. Put infant on floor frequently to play. (Very important to infant's further development).	
			15. When infant begins to sit insecurely, parents can sit behind infant holding gently by shoulders. Sing and rock infant gently from side-to-side just until arms touch floor. As infant begins to anticipate floor by putting arm out to touch floor, change rocking to forward and backward so infant can develop a sense of the continuity of floor. Move to different positions like being held on tummy and moved up and down to touch floor.	
			16. Teach infant to localize sound. -- When parents talk to infants, have the infant touch them as they talk and move. -- Have infant touch noise-making objects.	

NURSING CARE PLAN - VISUALLY IMPAIRED INFANT

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Be sure to bring infant's hand to object, NOT bring object to infant's hand.	
			16. Speak to infants before picking them up.	
			17. Touch back of hand/tips of fingers with an object before handing it to infant.	
			18. Do NOT use bouncing toys, rocking horses or infant walkers with blind infants.	
			19. Always describe to infants what caregiver is seeing.	
			20. Select play materials which foster development, hearing and touch.	
			21. Blind infants need to be taught to play.	
			22. Blind infants will take longer to learn to use a toy. This is a sign of vision deficit not intellectual capability.	
			23. Encourage parents to help infant play with other infants.	
			24. Encourage holding, cuddling, touching infant as much as possible and help parents identity cues that infant is recognizing and responding to individual care givers.	
			25. Give parents a great deal of positive reinforcement for their efforts.	

NURSING CARE PLAN - INFANT WITH HEARING LOSS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Lack of startle/blink reflex to a loud sound. Failure to awaken to loud noises during infancy. General indifference to sound. Response to loud sound instead of voice. Moro reflex past age 4 months. Failure to localize sound by 6 months. Monotone sounds. Lessened laughter. Less sound play and squealing. No babbling/inflections by 7 months. Vocal play, head banging, foot stamping for sound. Yelling/screeching. More visual alertness. Responds to visual stimulation more than verbal stimulation. Alert to gestures and movement. Little interest in verbal games.	Sensory-perceptual alterations related to hearing loss.	Parents are able to discuss their questions/concerns about having a hearing impaired infant. Parents are able to demonstrate attachment behaviors which aren't dependent on auditory awareness. Parents are able to demonstrate behaviors which will stimulate infant's development and receptive language.	1. Refer infant and family to: Montana School for Deaf & Blind 3911 Central Avenue 453-1401 Great Falls, MT 59401 2. Assess hearing using hear kit (See Resources for address) 3. Assist parents to understand what infant hears by simulating infant's type of hearing loss. -- Use of ear plugs - Mild hearing loss. -- Show a movie/video without sound. -- Place parents in sound-proof room and allow only to hear the frequencies the infant hears - selective hearing loss. -- Hearing a foreign language with no understanding of the language - central auditory imperception. 4. Explain that infant's general development, especially language development will be delayed. 5. Discuss with family that it is more important for infant to understand what is being communicated than to talk, so treatment is focused on receptive language first.	

NURSING CARE PLAN - INFANT WITH HEARING LOSS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Marked interest in things rather than people.			6. Assist family in setting realistic goals for infant.	
Family history of congenital deafness.			7. Explain that parents' active participation in early treatment program is critical to infant's development.	
Prenatal history of illness (diabetes, rubella) drugs eclampsia			8. Encourage parents to talk to infant normally but to emphasize face-to-face position, touching infant when talking to him/her. Emphasize visual cues when talking, and make facial expressions match language cues.	
Delivery and birth history				
Motor development				
Speech development				
Adaptive behavior			9. Auditory training program participation -- Montana School for Deaf and Blind -- Home training correspondence programs sponsored by: John T. Tracy Clinic 806 W. Adams Boulevard Los Angeles, California	
Play activities Temper tantrums Recent behavior/ personality change				
Results of hearing testing				
			10. Be sure both parents, older siblings, and other frequent caregivers available are involved in home training program.	
			11. Teach parents hearing aid care if hearing aid is in use.	

NURSING CARE PLAN - INFANT WITH HEARING LOSS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			Hearing aid casing:	
			-- Store away from high heat or excessive cold	
			-- Keep it dry - Remove during bathing, shampooing	
			-- Avoid dropping or bumping	
			-- Remove it when using hair spray or hair dryer	
			-- Turn switch to off before removing	
			Ear mold:	
			-- Keep it clean - detach it from receiver, wash in soap and water and dry completely	
			-- If opening becomes clogged with ear wax, remove wax with pipe cleaner	
			-- Do not use alcohol or other cleaning solutions	
			Batteries:	
			-- Store extra batteries in a cool, dry place	
			-- If stored in refrigerator, let warm to room temperature before use	
			-- Remove batteries from aid when not in use	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Keep battery contacts clean (remove residue with a pencil erasure)	
			-- Insert batteries correctly	
			-- Check periodically with a battery tester	
			Microphone:	
			-- Check microphone openings; if clogged, wipe off with dry cloth	
			-- Do not use damp cloth or pipe cleaner if holes are clogged - consult hearing aid dealer	
			12. Assist parents to promote optimum development in motor and social areas.	
			13. Encourage parents to talk to phone company and hearing/speech therapist about adaptive devices for hearing impaired infants and children.	
			14. Encourage parents to reward and encourage early efforts at language such as cooing, babbling, etc. by smiles, touch, and looks of pleasure and excitement.	
			15. Encourage parents to speak in increasingly longer, more complex sentences to infant.	

NURSING CARE PLAN - INFANT WITH HEARING LOSS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			16. Encourage parents to "read" picture books to infants.	
			17. Encourage infant to explore within safe boundaries.	
			18. Have infant feel parents throat when talking and when quiet.	
			19. Do not shout at infant.	
			20. Discuss importance of discipline and limit setting.	
			21. Expose infant to other hearing and deaf infants.	
			22. Stress infant's abilities not disabilities.	
			23. Encourage parents to hold, cuddle, and touch infant as much as possible.	
			24. Give parents a great deal of positive reinforcement for their efforts.	
			25. Encourage parents to voice their frustrations in caring for hearing-impaired infant.	
			26. Involve parents in local support group for hearing impaired children if available.	

RESOURCES

THE INFANT WITH PROBLEMS OF SENSORY REGULATORY MECHANISMS

1. American Council of the Blind (202) 833-1251
   1211 Connecticut Avenue N.W., Suite 506
   Washington, D.C. 20036

2. National Easter Seal Society (312) 243-8400
   2023 W. Ogden Avenue
   Chicago, Illinois 60612

3. American Foundation for the Blind (212) 620-2000
   15 W. 16th Street
   New York, New York 10111

4. National Society to Prevent Blindness
   79 Madison Avenue
   New York, New York 10016

5. Alexander Graham Bell Association
   for the Deaf
   3417 Volta Place
   Washington, D.C. 20007

6. Montana School for the Deaf and Blind (406) 453-1401
   3911 Central Avenue
   Great Falls, MT 59401

7. Montana State Library 1-800-332-3400
   930 E. Lyndale
   Helena, MT 59620

8. Visual Services Division (406) 444-2590
   Montana Department of Social and
   Rehabilitation Services
   111 N. Sanders
   Helena, MT 59604

9. Montana Association for the Blind (406) 755-6913
   P.O. Box 536
   Kalispell, MT 59901

10. Montana Association for the Deaf (406) 761-0769
    5309 - 7th Avenue South
    Great Falls, MT 59401

11. Montana Center for Handicapped Children (406) 657-2312
    Normal Avenue and Poly Drive
    Billings, MT 59101

12. Montana Easter Seal Society/Goodwill Industries (406) 761-3680
    4400 Central Avenue
    Great Falls, MT 59401

Bozeman	994-4563
Butte	782-0327
Billings	252-9606
Conrad	278-7558
Havre	265-6151
Helena	442-2061

13. Hear Kit
BAM World Markets, Inc.
P.O. Box 10701
University Park Station
Denver, Colorado 80210

14. Braille Institute (213) 663-1111
741 N. Vermont Avenue
Los Angeles, California 90029

15. National Association for (212) 889-3141
Visually Handicapped
305 E. 24th Street
New York, New York 10010

16. National Association for
Parents of Visually Impaired (512) 459-6672
P. O. Box 180806
Austin, Texas 78718

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VIII. THE DEVELOPMENTALLY DISABLED INFANT

OVERVIEW OF MENTAL RETARDATION

As health care and society's approach to the care of mentally retarded individuals change, nurses are becoming more actively involved in the care of the mentally retarded child and his/her family. In Montana particularly, the state has made a commitment to maintain mentally retarded children in their families and their communities. This commitment requires the availability of resources to assist the family to maintain and educate the mentally retarded child. Community health nurses play an active role in the resource network available to families.

The American Association on Mental Deficiency defines mental retardation as "significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period." (Grossman, 1977) The federal definition of developmental disabilities, as described in Public Law 95-602, Is a severe, chronic disability which:

-- is attributable to a mental or physical impairment or combination of mental and physical impairments;

-- is manifested before the person attains age 22;

-- is likely to continue indefinitely;

-- results in substantial functional limitations in three or more of the following areas of major life activity:

> self-care; learning; mobility; receptive and expressive language; self direction; economic sufficiency; and capacity for independent living and

-- reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated.

The future for the mentally retarded infant is much more positive than it was 20 years ago. It is known that mental retardation, one of the most common handicapping conditions, is not the terminal condition that was once thought. With early and active intervention, most mentally retarded infants can lead productive, semi-independent lives. The key to the future for the mentally retarded infant is early intervention. The goal of intervention is to maintain the infant, as much as possible, at age-appropriate developmental stages. To achieve this goal, the parents and all care-providers must assist the infant in reaching his/her maximum potential.

There are classifications of mental retardation which allow the care providers to begin developing a realistic plan of care for the mentally retarded infant. The classifications are: (American Association of Mental Deficiency)

Level	Preschool (0-5 years) Maturation and Development
Borderline	Has few, if any, developmental lags; often not detected until child begins having academic problems.
Mild	May not be "labeled" as mentally retarded by casual observer; Slower to walk, talk and take responsibility for self-care; Follows same developmental sequence as non-retarded children.
Moderate	Noticeable delays in motor development, especially speech; Learns various self-help activities such as dressing, feeding, toileting.
Severe	Severe delay in motor development: Very limited, if any, communication skills. May be able to learn very basic self-care skills such as self-dressing.
Profound	Gross retardation; very little functioning in sensorimotor areas; needs continuous care.

There are many causes for mental retardation since it is not a disease but a set of responses. About 94% (Ehlers, Krishef and Prothero, 1977) of incidents of mental retardation have unknown causes or are not able to be classified. Generally, there are nine broad categories of etiologies for mental retardation. They are: (Payne and Mercer, 1975)

1) Infection and intoxication (this includes rubella, syphilis, alcohol, nicotine or other drug consumption, exposure to industrial chemicals, toxemia, Rh incompatibility or lead poisoning).

2) Trauma (such as brain injury during pregnancy, labor, delivery or postpartum, lack of oxygen to brain, exposure to radiation).

3) Metabolic disorders (such as galactosemia, homocystinuria, hypothyroidism, maple syrup urine disease, or phenylketonuria).

4) Gross postnatal brain disease (neurofibromatosis, tuberous sclerosis).

5) Microencephaly, hydrocephaly.

6) Gestational disorders (prematurity, postmaturity, low-birth weight).

7) Psychiatric disorders which develop before a child reaches age 18.

8) Environmental influences (physical, social, or sexual abuse).

9) Genetic abnormalities (Down's syndrome, cri du chat syndrome).

Community health nursing care involves thorough assessment and planning. In areas where resources are limited, the CHN may have to initiate an infant stimulation and development program.

MENTAL RETARDATION

DEFINITION:

Significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period. (American Association on Mental Deficiency.)

PATHYOPHYSIOLOGY:

Variable

INCIDENCE:

Unknown.

RISK FACTORS:

A. Infections and intoxications.
B. Trauma.
C. Metabolic disorders.
D. Gross postnatal brain disease.
E. Microencephaly, hydrocephaly.
F. Gestational disorders.
G. Genetic abnormalities.

ONSET:

Federal definition - Any time between birth and age 22.

SYMPTOMS:

Delayed development

MEDICAL MANAGEMENT:

A. Early identification of developmental delays.
B. Developmental assessment of infants at risk for developmental delays.
C. Referral of infants at-risk to appropriate community resources.

NURSING GOALS:

A. Early identification of infants-at-risk.
B. Promotion of development in infants-at-risk and identified infants.
C. Assist families to set realistic goals for infants.
D. Promote healthy resolution of grief response.
E. Provide interventions to promote bonding.

DOWN'S SYNDROME (TRISOMY 21)

DEFINITION:

A genetic defect caused by chromosomal abnormality of #21 chromosome.

PATHOPHYSIOLOGY:

Genetic defect of #21 chromosome which gives the characteristic features of the infant with Trisomy 21.

INCIDENCE:

1 to 600-650 live births.

RISK FACTORS:

A. Maternal age over 35 years old.
B. Early maternal aging.
C. Family history of Down's Syndrome.

ONSET:

Immediately after birth.

SYMPTOMS:

A. Small, rounded head with a flat occiput. May have sparse hair, tends to have a flat profile.

B. Inner epicanthal folds with an upward, outward eye slant, speckled iris and short, sparse eyelashes.

C. Ears may be low set, usually small.

D. Nose - flat nasal bridge.

E. Mouth and teeth - Protruding tongue, poorly developed mandible, high arched palate, delayed eruption of teeth and orthodontia problems common.

F. Neck - Short, broad neck with loose lateral skin folds.

G. Skin - Tends to be dry, cracked, mottled.

H. Hands - Short; broad with short fingers, incurved little finger transverse palmar crease.

I. Muscles - Lax joints with poor muscle tone.

J. Abdomen - Protruding. Umbilical hernias and diastasis recti very common.

K. Genitalia - Undescended testes, small penis in males. Enlarged vulva in females.

L. Feet - Short, broad with a wide space between big and second toe and plantar creased.

M. Brain - Smaller than normal especially cerebellum and brain stem and expressive language skill.

MEDICAL MANAGEMENT:

A. Identification and treatment of secondary problems - eye, ear and respiratory infections, heart and gastrointestinal defects.

B. Referral for genetic counselling.

C. Referral to community resources to promote normal development.

NURSING GOALS:

A. Support parents during diagnosis and subsequent grieving.

B. Provide interventions to promote bonding.

C. Prevent physical problems associated with syndrome.

D. Assist families in setting realistic goals and making future plans for infant.

E. Promote optimum development in infant.

FETAL ALCOHOL SYNDROME

DEFINITION:

Symptoms caused by maternal consumption of alcohol during pregnancy.

PATHOPHYSIOLOGY:

Damage to developing embryonic cells caused by exposure to alcohol.

INCIDENCE:

Full Syndrome:	1 in 750 live births
Effects of alcohol:	1 in 100 live births

RISK FACTORS:

Mother who consumes alcohol during pregnancy.

ONSET: Variable.

SYMPTOMS:

A. Small head.
B. Narrow palpebral fissures.
C. Short, upturned nose.
D. Abnormally small jaw line/jaw line which projects beyond forehead.
E. Flaccid, poor muscle tone.
F. Poor coordination.
G. Severe irritability.
H. Mental retardation.

MEDICAL MANAGEMENT:

A. Early identification of maternal alcohol consumption.
B. Early identification of infant with F.A.S.
C. Referral of family to appropriate community resources.

NURSING GOALS:

A. Provide interventions to promote bonding.
B. Promotion of optimum development in infant.
C. Development of family strategies to cope with severe irritability in infant.
D. Referral of alcoholic family members to community resources.
E. Close follow-up for child abuse, neglect, and other dysfunctional family coping methods.

NURSING CARE PLAN - DEVELOPMENTAL DISABILITIES

Assessment	Nursing Diagnosis	Goal	Plans	Date Completed and Initials
Observable slowness in accomplishing these normal developmental tasks: Socialization -- Smiling -- Vocalizing -- Attention seeking toward care-givers -- Manipulates toys and other objects -- Responds to simple interactive games such as "Peek-a-boo" or "Pat-a-cake" Language -- Vocalizes in response to others -- Repeats sounds and syllables -- Carries out simple commands -- Uses single words for objects Self-help -- Sucks and swallows -- Reaches, holds and directs bottle if bottle-fed -- Indicates hunger needs if breast-fed -- Eats baby food and progresses to mashed and soft table foods -- Drinks from cup held by parent and progresses to holding own cup -- Feeds self - finger foods -- Holds out arms and legs while being dressed. Cognitive skills -- Removes cloth from face -- Looks for object which has been removed from sight -- Takes object out of container -- Puts objects in containers -- Transfers object from one hand to another -- Drops and picks up objects -- Finds tags/objects hidden out of sight	Alteration in development related to diminished brain activity.	The infant is able to meet developmental tasks appropriate to an infant 12 months of age or younger. The parents are able to describe the infant stimulation and developmental activities necessary to promote optimal development. The parents are able to modify the infant's environment to promote optimal development and provide for infant's safety.	1. Assess developmental level -- Do assessment when care-givers are able to observe and assist. -- Do assessment when infant is fully awake. -- Avoid doing assessment when infant is hungry, wet, tired or ill. -- Do assessment in home whenever possible. -- Explain thoroughly the purpose of the assessment. -- Encourage parents to ask questions and verbalize concerns. -- Explain to parents that infant will not be able to complete all tasks and that the infant's inability to complete tasks assists the tester in knowing exactly what the infant can accomplish and where intervention might be used most optimally. -- Explain clearly the results of the developmental assessment. -- Work with the parents in developing a plan to enhance the infant's development. -- Use one of the following developmental assessment tools. -- Portage Guide to Early Education Portage Project CESA 12 Box 564 Portage, Wisconsin 53901 -- The Washington Guide to Promoting Development in the Young Child, by Barnard, K.E. and M.L. Erickson in Nursing Care of Infants and Children, Whaley, L.F. & D.L. Wong, St. Louis, C.V. Mosby Co., 1983. -- The Bayley Scales of Infant Development The Psychological Corporation New York, New York 1969 2. Assess the infant's home/social environment. Tools which may be used include: -- H.O.M.E. - Home Observation for Measurement of the Environment (Birth to Three) 1976 by Dr. Bettye M. Caldwell, The Center for Early Development and Education, University of Arkansas, 814 Sherman St., Little Rock, Arkansas 72202 Copy of this can be found in Whaley and Wong, Nursing Care of Infants and Children, St. Louis, C.V. Mosby Co., 1983 p. 1632-1636. -- For infants under one month of age: The Neonatal Perception Inventory by Dr. Elsie R. Broussard. University of Pittsburgh, Graduate School of Public Health Pittsburgh, Pennsylvania 15261	

Assessment	Nursing Diagnosis	Goal	Plans	Date Completed and Initials
-- Carries out simple gesture on request (ex. "Point to your nose") Motor skills -- Head and chest supported on arms while on stomach -- Develops head control while sitting -- Rolls over -- Pulls to sitting with help, progresses to sitting by self -- Turns head freely when sitting with support -- Progresses from standing with help to standing alone -- Uses pincher-grasp when picking up objects -- Licks food around mouth -- Turns pages of books several at a time -- Scoops using spoons or shovels -- Progresses from walking along furniture to walking unassisted			-- Carey Infant Temperament Questionnaire by Dr. William Carey 319 W. Front Street Media, Pennsylvania 19063 3. Develop plans to assist infant in meeting next set of age-appropriate developmental tasks. -- Plans must begin with skills that are appropriate for the infant's skill level (example - helping the 8 month old infant to develop head control before learning to roll over, sit or walk). -- Plans must be agreeable to the parents and able to be carried out by the parents. -- Use Portage Guide or Washington Guide for suggested activities to develop specific skills. 4. Review with parents, expectations for infant's development. 5. Assist parents in setting realistic goals for infant based on development. 6. Review, with parents, infant's need for play (needs are mostly the same as for non-retarded infants) -- Sensori-motor play may be prolonged. -- Parents should expose infant to as many different sights, sounds, and sensations as possible. -- Infant should be taken on outings such as to grocery store, shopping center. -- Infant should be held, cuddled, rocked, talked to en face position, etc. -- Toys should be selected for educational value. Suggested toys for infants under one year: -- Rattles, bells -- Big balls -- Blocks -- Musical toys -- Stuffed toys -- Stacking toys -- Review with parents safety considerations with toys -- Appropriate for age and developmental level -- Unbreakable -- No small, removable parts -- Must be non-toxic -- No sharp edges, points, corners -- No exposed mechanical parts -- No batteries -- Avoid balloons	

Assessment	Nursing Diagnosis	Goal	Plans	Date Completed and Initials
			-- Remind parents that many retarded infants will not initiate appropriate play activities on their own. As a result of boredom they may begin self-stimulation activities such as rocking, head-banging, finger-sucking, masturbation -- Distract infant if self-stimulation occurs with another activity. -- Ignore self-stimulation 7. Explain to parents that retarded infants need discipline the same as all infants. Discipline helps infants develop a sense of security and self-control. -- Limit setting must be simple, consistent and appropriate for age -- Avoid long explanations about the why of actions. -- Behavior modification techniques can be used very effectively to change undesirable behaviors. 8. Socialization - Parents should be encouraged to set the same expectations in respect to social behavior as any of their children. -- Infants should respond to their own names -- Wave good-bye -- Say hello, thank you, please, etc.	
Shape of infant's mouth Control of mouth, lips Tongue movement - forward, backward, side-to-side. Head and trunk support Firmness of grasp Ability to reach for an object, hold it and release it Type of formula, calories/ounce Length of feedings Frequency of feeding 3 day dietary history kept by parents	Alteration in nutrition: less than body requirements related to poor oral muscle tone and poor coordination of suck, swallow, gag reflexes.	Parents able to demonstrate feeding techniques. Infant maintains height and weight normal for age.	1. If infant has nasal congestion, suction nares with bulb syringe. Thick mucous can be thinned with a dilute saline solution. 2. Explain to parents that tongue thrusting doesn't mean a rejection of food or parents. 3. Calculate caloric needs on the basis of height, weight and activity level not on chronological age. 4. Monitor height, weight and head circumference monthly for first six months of life and then every other month until one year. Use Down's growth grids when available. 5. Schedule small, frequent feedings with rest periods between feedings. 6. To strengthen oral muscles. -- Play tongue games to increase tongue control (ex. stick out tongue, move from side-to-side, etc.) -- Let infant blow bubbles with bubble solution or blow water through a straw, blow feather. 7. When beginning solid food - Place food to the back and side of mouth. 8. Use long straight-handled infant spoon.	

NURSING CARE PLAN - DEVELOPMENTAL DISABILITIES

Assessment	Nursing Diagnosis	Goal	Plans	Date Completed and Initials
Skin color, texture turgor, vascularity, moisture, temperature Lesions Type, location, size, shape, color, distribution and drainage	Potential impairment of skin integrity related to dry, cracked skin.	Infant's skin is smooth, moist and elastic. Parents can demonstrate skin care techniques.	1. Bathe infant 2-3 times per week (Use wash cloth and warm water to clean diaper area daily and after each bowel movement). 2. Avoid use of soap (If you must use soap, use a mild, nondetergent soap without perfumes, anti-perspirants), such as Ivory. 3. Do not use powders of any kind. 4. Use topical creams to keep skin moist.	
Respiratory rate, rhythm, depth, type of respiration. Cough-frequency, type Breath sounds on auscultation Nasal flaring Retractions Sternal Suprasternal Intercostal Pulse rate, rhythm, quality Skin color	Alteration in respiratory function related to infants increased susceptibility to respiratory infections.	Parents are able to prevent respiratory infections. Infant is able to sustain optimal movement of air in and out of the lungs. If infant gets an infection, the parents are able to demonstrate skills necessary to care for infant.	1. Prevention -- Handwashing by care givers before doing any care of infants. -- Avoid people with "colds". -- Never put infant in bed with bottle (may facilitate the development of otitis media). -- Increase humidity in home - use cool-mist humidifier. -- Follow each bottle feeding with a clear water feeding. (Non-hungry infants may only take a few swallows). 2) Care of infant with respiratory infection: -- Elevate head of crib bed by putting pillow between mattress and springs. -- Put cool-mist humidifier in infant's room. -- Teach parents how to clean nares before feedings using a bulb syringe. -- Teach parents percussion and drainage. -- Parents do percussion and drainage four times a day. -- Change infant's position every two hours. -- Teach parents proper administration and storage of medication.	
Parents' willingness to hold baby, talk to, cuddle, and play with her. Maintenance of eye contact. Response to baby's needs when crying.				

NURSING CARE PLAN - DEVELOPMENTAL DISABILITIES

Assessment	Nursing Diagnosis	Goal	Plans	Date Completed and Initials
Parents' willingness to take baby out of house, have friends in to visit. Parents refer to baby by name? Parents' intellectual, physical, and emotional ability to provide normal infant care as well as meeting special needs of infant. Parents express feelings of disgust, disappointment, or displeasure toward infant. Parents keep baby in portion of home away from family activities. Do not initiate movement of child from room to room, in order to maintain physical contact.	Alternation in parenting: bonding related to special needs of infant or guilt or grieving the loss of a perfect newborn.	Parents will: Demonstrate increased attachment behaviors Begin to verbalize positive feelings toward infant Incorporate infant into family constellation and activities.	1. Show interest in baby, commenting on what she is doing, how she looks. Stress the normal things about her appearance and activities. 2. Encourage parents to verbalize negative feelings. 3. Demonstrate how to hold and cuddle baby who is "floppy". Explain that this helps baby to feel more secure. Swaddle baby in blanket when holding on lap. 4. Encourage family to include infant in family activities, to move baby from room to room with them in order to provide contact, stimulation, play. 5. Give parents positive reinforcement for the care they are providing. 6. Role-play potentially awkward situations parents may encounter in public in order to help them cope with questions, stares, and negative reactions to child. Encourage parents to express their feelings about embarrassing or painful experiences with strangers. 7. Discuss need for respite care. Assist in finding resources for care givers or sitters. 8. Encourage parents to become involved in Special Olympics, parent groups with similar problems to provide for sharing, resources, and support. 9. Observe for signs of child abuse and neglect.	

RESOURCES

THE INFANT WITH DEVELOPMENTAL DISABILITIES

1. Association for Children with
   Down's Syndrome
   2616 Martin Avenue
   Bellmore, New York 11710 (512) 221-4700

2. Association for Retarded Citizens
   2501 Avenue J.
   Arlington, Texas 76011 (817) 640-0204

3. Association for the Severely Retarded
   7010 Roosevelt Way, N.E.
   Seattle, Washington 98115 (206) 523-8446

4. Mental Retardation Association of America
   211 E. Third Street, #212
   Salt Lake City, Utah 84111 (801) 328-1575

5. National Council on Alcoholism
   733 Third Avenue
   New York, New York 10017

6. National Clearinghouse for
   Alcohol Information
   P.O. Box 2345
   Rockville, Maryland 20852

7. National Down's Syndrome Society
   146 East 57th Street
   New York, New York (212) 421-9800

8. Pamphlet - Alcohol and your Unborn Baby
   (ADM) 81-521 Single copy - Free
   National Clearinghouse for Alcohol
   Information
   Box 2345
   Rockville, Maryland 20852

9. Department of Social and Rehabilitative
   Services
   111 N. Sanders
   Helena, Montana 59601 (406) 444-2490

   Developmental Disabilities Division 444-2955
   T.R.I.C. Training Resource and
   Information Center 444-5647

10. Eastern Montana College
    Department of Special Education
    Billings, MT 59101
    Staff consultants and
    library materials

11. Montana State University
Department of Home Economics — Curriculum materials,
Bozeman, MT 59715 — consultants, workshops

12. Montana University Affiliated Program — (406) 243-5467
University of Montana — Developmental disabilities
Missoula, Montana 59812 — materials, curriculum
development and workshops

13. Office of Public Instruction,
Special Services
State Capitol
Helena, Montana 59601 — (406) 444-3693

14. Developmental Disabilities Planning — (406) 449-8325
and Advisory Council
111 N. Sanders
Helena, Montana 59604

15. Region II Child and Family Services
1500 9th Avenue, South
Great Falls, Montana 59405 — (406) 452-9531

16. Family Outreach, Inc.
825 Helena Avenue
Helena, Montana 59601 — (406) 443-7370

17. Developmental Education
Assistance Program
Box 989
Miles City, Montana 59301 — (406) 232-6034

18. Developmental Assessment Services
E. Little Street
Glendive, Montana 59330 — (406) 365-6031

19. Hi-Line Home Programs
P.O. Box 469
Glasgow, Montana 59330 — (406) 228-9431

20. Montana Association for
Retarded Citizens
Helena Peterson: President
1723 Iris Lane
Billings, Montana 59102 — (406) 259-5052

21. Montana Center for Handicapped Children — (406) 657-2312
Normal Avenue and Poly Drive
Billings, Montana 59101

22. Montana Society for Autistic Children*
3125 Avenue F (406) 656-8053
Billings, Montana 59102 *Not all autistic children are retarded.

23. Parents Coalition for Handicapped Children
Montana Center for Handicapped Children
Normal Avenue and Poly Drive
Billings, Montana 59101 (406) 657-2312

24. March of Dimes Many pamphlets on retardation

A) North Central Division
Mavis Peterson: Executive Director
101 Central Avenue
Great Falls, Montana 59401 (406) 453-7071

B) Rocky Mountain Chapter
Wanda Person: Executive Director
5 East 15th Street
Helena, Montana 59601 (406) 442-5018

C) Big Sky Chapter
Patty Clapper: Executive Director (406) 252-7480
P.O. Box 457
Billings, Montana 59103

25. Shodair Lay Lending Library
840 Helena Avenue
Helena, Montana 59601 (406) 442-1980

26. *Caring, Inc. (newsletter) (206) 922-8194
P.O. Box 400
Milton, Washington 98354
Sharon Shimizu, Executive Director
Contact: Tina Tossey

27. *National Down Syndrome Congress (newsletter) (312) 226-0416
1640 West Roosevelt Road
Chicago, Illinois 60608
Diane M. Crutcher, Executive Director

28. *National Down Syndrome Society (newsletter) (212) 764-3070
70 West 40th Street (800) 221-4602
New York, New York 10018
Donna M. Rosenthal, Executive Director

29. For more resources and a comprehensive list of books, articles, pamphlets, films, etc., see:

Prevention Resources for Birth Defects and Mental Retardation
A Guide for Teachers and Human Services Professionals
Development Disabilities Planning and Advisory Council
111 North Sanders
Helena, Montana 59604

30. "Developing Potential"
Attention: Linda Schell, Program Coordinator
Medicenter One, Inc.
300 North Seventh Street
Bismark, North Dakota 58501 (701) 224-6000

"Developing Potential" is an evaluation and treatment program for individuals who have an existing or possible physical, mental or emotional handicap. The age span included in the program is birth to 21 years.

Patients who have any of the following disabilities, developmental delays or problems may benefit from the services offered in "Developing Potential":

Perinatal high risk factors
Neurologic impairments
Minimal cerebral dysfunction
Trauma/abuse
Neuromuscular disorders
Learning disorders
Behavioral disorders
Congenital/genetic abnormalities
Orthopaedic conditions
Failure to thrive
Cardiopulmonary disorders
Sensory impairments
Communication disorders
Mental retardation

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Fraiberg, S.H.: The Magic Years. 1959, Charles Scribner's Sons, New York.

Gordon, I.J.: Baby Learning Through Baby Play. 1970, St. Martin's Press, New York.

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Hymovich, D.P. and Barnard, M.V.: Family Health Care. 1973, McGraw-Hill Book Company, New York.

Ilg, F.L., Ames, L.B.: Child Behavior From Birth to Ten. 1955, Harper and Row Publishers, New York.

McPherson, M., Hutchins, V.L.: Home Care For Infants With Serious Handicapping Conditions. 1984, Association for the Care of Children's Health, Houston, Texas.

Munnion, C.: The Open Home. 1976, St. Martin's Press, New York.

Stephens, C.J.: The Fetal Alcohol Syndrome: Cause For Concern. Maternal-Child Nursing: 6:251-256, July/August, 1981.

Raff, B.S., Carroll, P.: Social Support and Families of Vulnerable Infants, 20:5, 1984, March of Dimes.

Glassman-Feibusch, B.: The Nurse's Role With Mentally Retarded Clients: Teacher, Advocate, Listener, Doer. Journal of Community Health Nursing 1(4):225-6, 1984.

Farnham, R.: Nursing Intervention in Grief Resolution. . . Mothers of Retarded Children. Nevada RN formation ( ):5, 11, 13, November, 1984.

Spencer, K.: More Than Lip Service . . . to Help Mentally Handicapped People Develop Skills . . . Individual Program Plans. Nursing Mirror, 159(22), December 12, 1984.

IX. THE INFANT WITH PROBLEMS OF OXYGEN/CARBON DIOXIDE EXCHANGE

BRONCHOPULMONARY DYSPLASIA

DEFINITION:

Damage to the epithelium of the lungs in both full-term and premature infants who have been treated with oxygen therapy and/or mechanical ventilation.

PATHOPHYSIOLOGY:

A. Thickened and increased amount of fibrous connecting tissue in the alveolar walls.

B. Increase in the size and number of squamous cells in the bronchi.

C. Paralysis of the cilia of the respiratory tract caused by high oxygen concentration.

INCIDENCE:

Varied from one NICU to another.

RISK FACTORS:

A. Mechanical ventilation.
B. Prematurity.
C. Need for high concentration of oxygen following birth.
D. Respiratory distress syndrome.

ONSET:

Shortly after birth.

SYMPTOMS:

A. Increased mucous production.
B. Immature cough reflex which reduces ability of lungs to clear mucous.
C. Cyanosis.
D. Dependence on low levels of oxygen.

MEDICAL MANAGEMENT:

A. Management of oxygen levels.
B. Aggressive management of infections.

NURSING GOALS:

A. Teach parents how to manage infant on long-term oxygen care at home.
B. Assist families to find financial and community resources, especially emergency backup (fire department, etc.) and respite care.
C. Provide support to the families.
D. Coordinate use of equipment (respiratory therapy) and evaluate.
E. Assist family in bonding with infant following prolonged separation in NICU (See Nursing Care Plan for High Risk Infant).

APNEA/SUDDEN INFANT DEATH SYNDROME (SIDS)

DEFINITION:

Lapse of breathing for 20 seconds or more followed by color change and bradycardia. May recover spontaneously or with treatment, or may die if undetected (Sudden Infant Death).

PATHOPHYSIOLOGY:

A. Infants are not responsive to blood and cerebrospinal fluid levels of oxygen and carbon dioxide.

B. Neurons have fewer dendrite associations causing reduced neurological activities.

INCIDENCE:

A. One third of all infants less than 32 weeks gestation.

B. Almost all infants less than 30 weeks gestation.

C. 10-15,000 infants a year experience a SIDS episode. Occurs in both full-term and premature infants.

RISK FACTORS:

A. Airway congestion.
B. Anemia.
C. Dehydration.
D. Hypo/hyperthermia.
E. Sepsis.
F. Seizures.
G. CNS depression from medications.
H. Intracranial hemorrhage.
I. Heart failure.
J. Respiratory distressed infants who are tiring.
K. Prematurity.
L. Low birth weight.
M. Recent prolonged apnea or apneic periods treated with theophylline.
N. Hyaline membrane disease.
O. History of a SIDS episode from which recovered.
P. Family history of SIDS (especially brothers and sisters).

ONSET:

Apnea in newborns, usually within 11 days after birth.
Highest incidence of SIDS between 1-8 months of age.

SYMPTOMS:

A. Breathing lapse of 20 seconds or more.
B. Cyanosis.
C. Heart rate of below 100 B.P.M.

MEDICAL MANAGEMENT:

A. Support of families with infant apnea monitors.
B. Aggressive treatment of factors which predispose infants to apnea.

NURSING GOALS:

A. Teach family use of apnea monitor and theophylline.
B. Assist families to prepare a safe environment for apneic infants.
C. Teach/review infant CPR for all who will care for infant.
D. Provide emotional support to families.
E. Assist in contacting community resources for financial assistance, emergency backup (fire department, etc.), respite care.
F. Coordinate use of equipment (respiratory therapy) and evaluate.
G. Assist family in grieving if sudden infant death has occurred. (See Nursing Care Plan for Terminally Ill Infant).
H. Assist family in bonding with infant who has a life-threatening problem (see Nursing Care Plan for High-Risk Infant).

NURSING CARE PLAN - INFANT WITH BRONCHOPULMONARY DYSPLASIA

Assessment factors	Nursing Diagnosis	Goals	Plans	Initials & Date done

Home
-- Telephone
-- Heat
-- Electricity
-- Running water
-- Transportation
 	
Family
-- Financial resources
-- Respite support for care of infant when parents away
-- Desire to become involved in care of infant.
-- Care and support of other children (resources)
-- Family knows of sources for equipment and supplies
 	
Infant
-- Respiratory rate, rhythm and depth.
-- Auscultation of all lung fields (diminished, absent rates, wheezing or rubs)
-- Percussion of lung fields
-- Heart rate (Apical) and rhythm
-- Skin color (nails, oral mucous membranes)
-- Findings of lab work
  -- Peak and trough levels of Theophylline
  -- Transcutaneous oxygen monitoring
  -- Nasal flaring
  -- Retractions (suprasternal, sternal or intercostal)
  -- Clubbing of fingers
	Alteration in respiratory function related to damaged epithelium of the lungs.	Parents able to verbalize all components of infant's respiratory care upon first visit.
		
		Parents able to demonstrate appropriately all components of infant's respiratory care within 1 week of discharge.
		
		Family able to incorporate all components of infant's safety or family's integrity within 3-6 weeks after discharge.
		
		Parents have made contact with community resources within 3-6 weeks after discharge.
			Assess family's ability to explain:
			
			What's wrong with infant
			
			Medications child is on and side effects.
			Theophylline
			-- Water based preparations or slow release gyrocaps are tolerated better than alcohol based preparations.
			-- If microlaboratory facilities available - peak and trough levels should be done regularly.
			-- Side effects of restlessness, irritability, flushing, tachycardia, urinary frequency, vomiting, nausea, should be reported to health care provider immediately.
			
			Furosemide (Lasix) - May be used to reduce pulmonary edema.
			-- Should not be discontinued suddenly.
			-- Serum electrolytes should be monitored monthly.
			-- Infant should be weighed daily.
			-- Chest sounds should be monitored weekly x 1 month and then monthly.
			-- Side effects of hypokalemia, dehydration, vomiting, diarrhea, and constipation should be reported to health care provider immediately.
			
			Safe use of Oxygen in the home - p02 levels should be measured monthly.
			-- No smoking
			-- Appropriate placement of nasal cannula
			-- Service provides, maintains the oxygen
			-- Oral Hygiene for users of oxygen
			
			Explanation of what other respiratory routines the child is on.
			-- Suction and equipment care
			-- Percussion and drainage
			-- Transcutaneous oxygen monitoring is done regularly at two weeks after being home and monthly thereafter. If child is under six months of age - a reading from the tranocutaneous oxygen monitor should be done when infant is asleep.
			-- Routine chest x-rays should be done at 4-6 month intervals. Abnormal x-rays will often persist for up to two years after birth.	

Assessment factors	Nursing Diagnosis	Goals	Plans	Initials & Date done
			2. Have family demonstrate all components of respiratory care in home. -- Check medications, dosage, amount. -- Check medication storage. -- Percussion - Use of hands is not effective in small infants. May use a cup made for percussion or may use a padded electric toothbrush. Be sure parents cover all lung fields when doing percussion. Also, be sure infant is lying head down and on side at appropriate intervals during percussion. -- Suctioning - Parents demonstrate care of equipment and proper suction techniques. Be sure parents wash hands before doing suction procedure. Be sure equipment is washed and cleaned every 12-24 hours. Glass and stainless steel without rubber parts may be placed in a dishwasher. -- Placement of Cannula -- Cannula can be kept in place by placing stoma-adhesive on each cheek and then tape the cannula to the stoma-adhesive. This can be changed once a week. -- Cannula can also be kept in place by putting a cap with ear flaps on child and pinning the cannula to each ear flap. -- Nasal prongs cause skin breakdown and don't stay in place. -- Use a #8 feeding tube inserted 6 mm into nares. -- Change nostrils at least once a day. -- Can also use a piece of tubing with multiple holes placed under the nose and fastened to stoma adhesive on cheeks. Then pin to shirt. -- Elevate head of crib 30°- 40°. This can be done by placing a foam wedge or pillows between the mattress and the crib springs. Infants can be kept up by then putting ½ of a sheet tucked under top of mattress and putting infant on top of sheet with part of sheet pulled up between infant's legs and pinned to make a sling. These infants should always sleep with head up in abdominal or side-lying position. -- Oxygen must be humidified. Have parents demonstrate cleaning and refilling of humidifier. Must be cleaned every 24 hours and refilled p.r.n.	

Assessment factors	Nursing Diagnosis	Goals	Plans	Initials & Date done
			-- Check to see if parents have made follow-up appointments, have financial resources to pay for equipment, medications and follow-up care, and have transportation to follow-up appointments.	
			3. Return visits -- Within 48 hours of discharge if possible -- Weekly for 8 weeks after discharge -- Monthly until child is 2 or parents terminate follow-up.	
			4. One or both parents certified in CPR for infants.	
			5. Teach parents how to take respiratory rate, rhythm and depth. Give parents normal range for infant's age.	
			6. Encourage parents to question and verbalize concerns, fears.	
			7. Review Oxygen safety precautions -- Post "No Smoking" signs -- Avoid smoking, fire, or sparks in infant's room -- Keep oxygen tank and infant's crib at least 5 feet away from heater, radiator -- Keep oxygen tank secured upright at all times -- Avoid use of alcohol, petroleum jelly (vaseline) or other petroleum-based products and aerosols -- Keep oxygen in a well ventilated area at all times -- If using an oxygen concentrator, do not use and extension cord and do not plug into outlets being used for other appliances	
			8. Be sure parents have notified phone, electric companies, ambulance/rescue squads, fire departments and first response teams of infant's status.	
			9. Review cleaning and maintenance of oxygen equipment supplies.	
			10. As child becomes able to tolerate nearly normal oxygen concentrations, the physician will order weaning to begin. Teach parents proper weaning procedure: Step 1. Turn off oxygen when child is awake, but not feeding. 2. Turn off oxygen during naps. 3. Turn off oxygen during feedings. 4. Turn off oxygen at night.	

NURSING CARE PLAN - INFANT WITH BRONCHOPULMONARY DYSPLASIA

Assessment factors	Nursing Diagnosis	Goals	Plans	Initials & Date done
Infant -- Medications infant is on (maybe Hydralazine, Methyldopa, Hydrochlorthiazide or Propranolol). -- Apical heart rate and rhythm. -- Blood pressure (use a doppler infant cuff) -- Neck veins (distended, flat) Lying Sitting -- Skin Color Temperature Presence of edema -- Fussiness during feedings -- Measurement of wrists and ankles. (Be sure you've recorded a baseline measurement).	Potential alteration in cardiac output related to right ventricular hypertrophy.	Infants blood pressure remains at 90/60 ± 20/20. Family able to verbalize signs and symptoms of alterations in cardiac output.	1. Take blood pressure weekly using a Doppler. 2. Assess parents understanding of medications and how to administer. Teach parents as needed. 3. Teach parents signs and symptoms of alteration in cardiac output (cyanosis, difficulty breathing, rapid, irregular pulse, blood pressure more than 115/90, fussiness during feedings, loss of appetite, swelling of hands and feet). 4. Remind parents to keep infant's head elevated during feedings. 5. Feed 1-2 ounces and then allow infant to rest for 3-5 minutes.	

NURSING CARE PLAN - INFANT WITH BRONCHOPULMONARY DYSPLASIA

Assessment factors	Nursing Diagnosis	Goals	Plans	Initials & Date done
1) Infant -- Feeding pattern (how much, how often) -- Formula (cal/oz., type of formula). -- Type of nipple used. -- Length and weight weekly -- Condition of hair, if any, skin, nails and mouth -- Strength of suck -- Swallowing -- Any spitting up - how much, how often. 2) Family -- Importance of infant weight gain to mother's image of "good mother"	Alteration in nutrition: less than body requirements, related to increased oxygen consumption and increased metabolic demands.	1) Infant gains 5-7 ounces weekly for first six months of life. 2) Birth weight doubled by six months of age. 3) Infant gains 3-5 ounces weekly for second six months of life.	1) Observe feeding time for: -- Parent-child interaction (watch for holding infant close to body, eye contact, positive verbalization from parents) -- Strength of infant suck -- Position infant held in -- Any vomiting, spitting up -- Any skin color changes, respiratory distress -- Note amount of formula taken, length of time spent feeding, any feeding difficulties. 2) Infant takes amount of formula. 12-18 oz. - Newborn 20-30 oz. - 2-3 months of age 25-35 oz. - 3-6 months of age 25-35 oz.+ - 6-7 months of age begin solids 24 oz. + solids - 7-12 months of age Adjust for prematurity. 3) Remind parents about the fact that these infants don't gain weight as quickly as other infants because their lung problems use up more energy that other infants put into gaining weight.	

NURSING CARE PLAN - INFANT WITH APNEA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Family history of apnea, SIDS, cardiac disease, chronic lung disease or seizures.	Alteration in respiratory function related to neurological immaturity and immature response to oxygen and carbon dioxide.	Parents able to describe care of infant with monitor.	1. Assess parents understanding of: -- Infant's medical diagnosis -- Infant's normal awake and asleep breathing patterns -- Apnea and sudden infant death syndrome -- Infant CPR -- Equipment maintenance, lead placement -- Sources for equipment replacement	
Infant history -- Gestation below 32 weeks -- Upper airway obstruction -- Seizures -- Vomiting following feeding -- Low birth weight -- Hyaline membrane disease -- History of a previous SIDS episode		Parents able to demonstrate care of infant with monitor.		
Periods of apnea of 15-20 seconds long, followed by cyanosis and bradycardia.			2. Review with parents the care of infant with monitor -- Have parents demonstrate putting the infant on the monitor -- Soft foam belt with leads on slightly below nipple line -- Leads should be off baby at least one hour every day with adult in constant attendance -- Use of an infant front pack when baby is not on monitor is recommended -- Notify fire department and power company about infant on monitor. Remind parents to do if they haven't done already	

NURSING CARE PLAN - INFANT WITH APNEA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed

			-- Must use monitor whenever not directly observing baby.
			-- Both parents or 2 adults in the home need to learn all care in order to lessen burden.
			-- Must always be within hearing range of alarm. (Can't take a shower if alone in house with infant, etc.)
			-- Check with parents to see if they have extra set of lead wires. Have phone number of monitor equipment dealer near phone.
			-- Skin care of infant
			    -- Wash black patches and baby's skin daily
			    -- No oil, lotions, creams should be used on baby's skin
			    -- Wash the belt in mild detergent and rinse well
			    -- Use fabric softener as this will reduce static interference in monitor
			-- Community health nurse should read the instructions which were sent with parents re: care of the infant with an apnea monitor	

NURSING CARE PLAN - INFANT WITH APNEA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Review with parents infant CPR -- Have parents keep diary of alarms and infant's condition after alarm. CHN check diary weekly Information which should be in diary: -- Medication, dose, time given -- Unusual changes in infant's activities -- Signs of illness (temperature above 101 rectally, cough, cold, vomiting, diarrhea, irritability) -- Unusual behavior (color changes, teething, new skills) -- Immunizations (date and what immunization) -- Changes in family activities (travel, illness) -- Events -- Date, time, number of beeps heard -- What was infant doing when parents got there? (was infant breathing, sleeping, crying, etc.) -- Apnea, bradycardia and/or tachycardia lights on	

NURSING CARE PLAN - INFANT WITH APNEA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- What parents did to end episode	
			Nothing - baby fine Gentle touch Gentle shake Vigorous shake CPR	
			-- How long was infant asleep before episode	
			-- Color changes in infant	
			-- Muscle tone - stiff, limp	
			-- Length of time since infant fed	
			3. Assess financial needs and refer as appropriate	
			4. If infant on medications:	
			-- Theophylline	
			Review method and time for administration. Side effects - especially watch for tachycardia.	
			-- Caffeine - Same parents' interventions as for Theophylline.	
			-- Blood levels should be drawn every 1-2 weeks unless indicated otherwise by the Apnea Center.	

NURSING CARE PLAN - INFANT WITH APNEA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			5. Daily telephone contact by CHN first week home then twice weekly for 2 weeks and then weekly thereafter. Home visits should be done weekly at least for first month home. 6. Indications for seeking discontinuance of monitor. -- No monitored events requiring stimulation or full resuscitation for three months -- No real alarms or self-resolving apnea for two months -- Normal pneumogram or thermistor study -- If SIDS sibling, at least six months of age Monitoring may be continued for one month beyond age of death of prior SIDS victim 7. See diagram for proper and improper monitor attachment 8. Suggestions for infant's room arrangement and supplies	

NURSING CARE PLAN - INFANT WITH APNEA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Place monitor on safe, sturdy, wooden surface near infant's crib. Make sure monitor is out of reach of other children. Do not set anything on top of monitor.	
			-- Place clip board near monitor for diary. Keep pen/pencil attached to clip board.	
			-- An intercom can amplify sounds in infant's room.	
			-- Keep path to baby clear and unobstructed.	
			-- DO NOT use extension cords with monitor. If parents' home doesn't have three prong outlets, parents need a three prong adaptor.	
			-- Keep flashlight next to monitor.	
			-- Monitor is very portable - take infant into rooms with other family members.	
			-- Be sure house address is visible from road and lit at night. If living in a rural area, send a map of house to local ambulance, fire department and First Response Team.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Subjective Data:	Parental anxiety related to life-threatening nature of infant apnea.	Parents able to verbalize feelings of anxiety.	1. Encourage parents to discuss concerns with health care providers.	
Manner of communication			2. Encourage parents to ask any questions.	
-- Thoughts confused or forgetful, lack of concentration or preoccupation with one thought	Depression related to isolation, family disruption, and fears for child's well-being.	Parents able to describe stress reduction strategies. Parents able to demonstrate stress reduction strategies.	3. Review care of infant with parents. 4. Telephone contact daily for one week after discharge. Two times per week for two weeks and then one time per week for 2-3 months.	
Focus of control				
-- Does fear interfere with lifestyle?	(Depression generally occurs after 3-6 months of apnea monitor use.)		5. Be sure family has emergency phone numbers prominently posted.	
-- Do the parents feel they can control the situation or do they look outside for control?			6. Assist family when ready to find babysitters to care for infant so parents can get out.	
Thought content			7. Teach parents signs of increasing fear and assist them in problem-solving.	
-- Can parents explain their fears? Are fears rational?			8. Teach parents stress reduction techniques	
Support systems			-- Progressive relaxation	
-- What or who are the parent's support system?			-- Use of reading and music to relax	
-- Can parents accept support from nurse or others?			-- Time management	
Objective data:			9. Refer parents to support group in community if available.	
-- Tense body posture -- Argumentative or defensive			10. Refer for family or marital counseling if necessary.	

NURSING CARE PLAN - INFANT WITH APNEA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
-- Rapid speech				
-- Muscle tightness				
-- Fatigue				
-- Increased pulse, BP, or respirations				
-- Nausea/vomiting				
-- Anorexia				
-- Urinary frequency				
-- Flushing/Pallor				
-- Insomnia				
-- Nightmares				
-- Forgetfulness				

Dangerous Situation

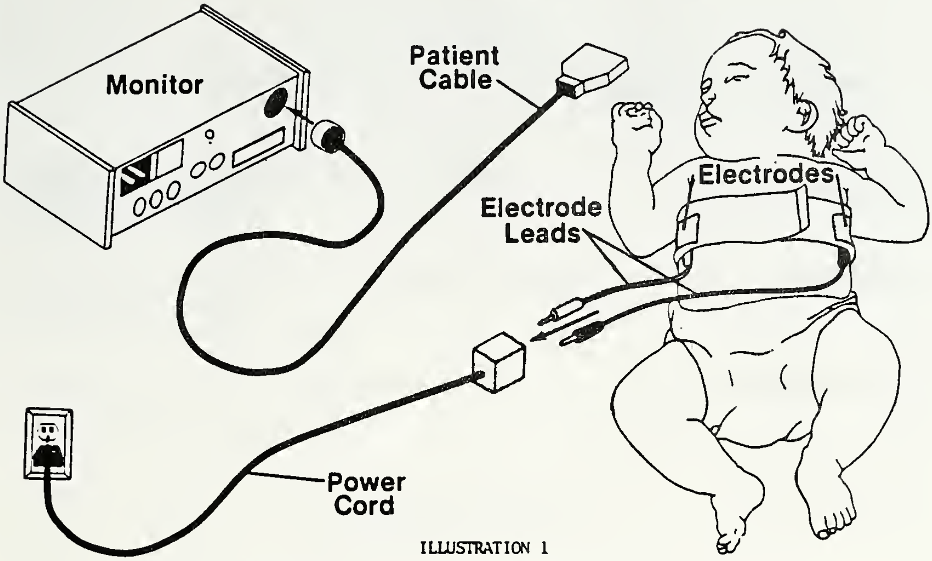

ILLUSTRATION 1

This picture shows a situation in which an accident can occur. The ELECTRODE LEADS can be incorrectly plugged into a POWER CORD instead of into the PATIENT CABLE as shown in illustration 2 below. Accidents also can occur when the ELECTRODE LEADS are plugged into other kinds of POWER CORDS, such as extension cords, or into wall sockets.

Correct Connections

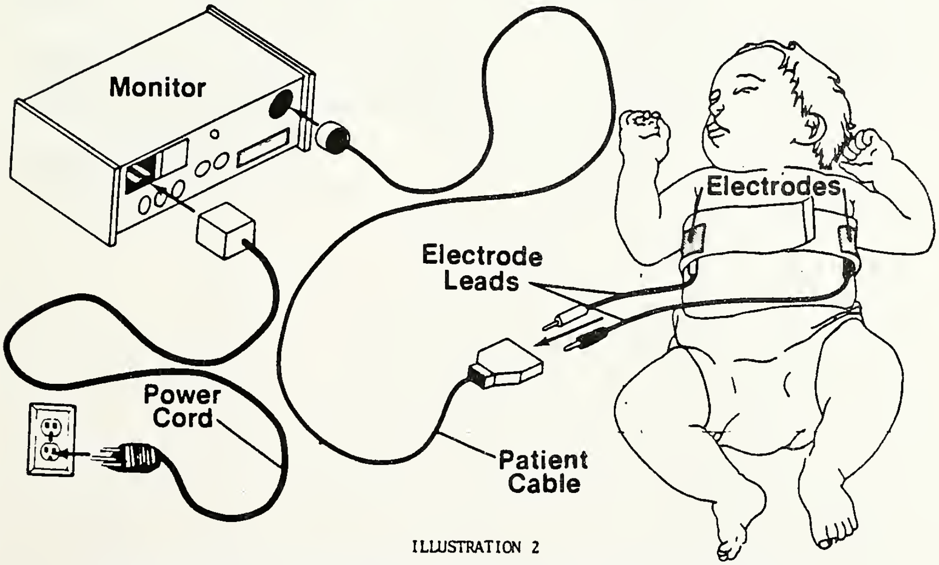

ILLUSTRATION 2

This picture shows the correct way to connect the infant to the MONITOR. The ELECTRODE LEADS are plugged into the PATIENT CABLE which in turn connects to the MONITOR. The MONITOR is connected to the wall socket by the POWER CORD.

RESOURCES

THE INFANT WITH PROBLEMS OF OXYGEN/CARBON DIOXIDE EXCHANGE

1. American Lung Association of Montana
825 Helena Avenue (406) 442-6556
Helena, MT 59601

2. Pediatric Pulmonary Association of America (404) 993-5859
150 North Pond Way
Rosewell, Georgia 30076

3. Health Information Clearinghouse 1-800-336-4797
P.O. Box 1133
Washington, D.C. 20013

4. Parents Coalition for Handicapped Children (406) 657-2312
Montana Center for Handicapped Children
Normal Avenue and Poly Drive
Billings, Montana 59101

5. Shodair Hospital Lay Lending Library (406) 442-1980
840 Helena Avenue
Helena, Montana 59601

6. National Sudden Infant Death
Syndrome Foundation (312) 663-0650
310 South Michigan Avenue
Chicago, Illinois 60604

7. Handicapped Children's Services (406) 444-4740
Family/MCH Bureau
Montana Department of Health and
Environmental Sciences
Cogswell Building
Helena, Montana 59620

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X. THE INFANT WITH PROBLEMS OF PRODUCTION AND CIRCULATION OF BLOOD

ANEMIA

Definition:

A. Reduction of red cell volume
B. Reduction of hemoglobin concentration
C. Indication/manifestation of underlying disease

Pathophysiology:

A. Increased loss or destruction of red blood cells (hemorrhage or sickle cell disease)
B. Impaired or decreased rate of production of red blood cells (iron deficiency anemia)

Incidence:

3-24% of all infants 6-24 months of age

Risk factors:

A. Prematurity
B. Blood loss
C. Bottle-feeding without iron supplement
D. Limited economic resources

Onset:

A. 6-9 months of age

Symptoms:

A. Muscle weakness, weak suck
B. Sleepiness
C. Pale, waxy skin color
D. Irritability
E. Apathy - poor eating
F. Delayed growth

Medical Management:

A. Diagnostic tests

   1) Red blood count (R.B.C.)
   2) Hemoglobin (Hb)
   3) Hematocrit (Hct)
   4) Mean corpuscular volume (MCV)
   5) Mean corpuscular hemoglobin (MCH)
   6) Mean corpuscular hemoglobin concentration (MCHC)

B. For nutritional anemia - Replacement of the specific nutrient
C. For anemia from blood loss - Replacement of the blood
D. Severe anemia - Supportive therapy including oxygen, replacement of blood, I.V. fluids and bed rest. (Usually implies hospitalization)

Nursing Goals:

A. Obtain a thorough health history including a specific dietary history
B. Teach family about medications, dietary sources of iron, and prevention of infection
C. Teach family about the importance of rest and energy conservation during treatment of anemia

SICKLE CELL ANEMIA

Definition:

A disease where normal hemoglobin is replaced by abnormal hemoglobin which causes a sickle-shaped red blood cell. This impairs the red blood cell's ability to carry oxygen.

Pathophysiology:

A. Autosomal-recessive disorder
B. Increased blood viscosity caused by entanglement of sickle-shaped red blood cells
C. Increased red blood cell destruction
D. Spleen loses its ability to filter bacteria and to promote the release of large numbers of phagocytic cells
E. Liver cirrhosis can occur
F. Kidney-Hematuria, enuresis and inability to concentrate urine
G. Osteoporosis
H. Osteomylitis
I. Many skeletal abnormalities
J. Stroke
K. Headache, aphasia, weakness, visual disturbances
L. Convulsions
M. Cardiac problems

Incidence:

A. Found primarily in blacks and people of Mediterranean descent
B. 7-13% of American blacks
C. Ratio 1:400 American blacks

Risk Factors:

A. Family history of sickle-cell disease or trait
B. Black or Mediterranean descent

Types:

A. Sickle cell trait (sicklemia) - Heterozygous
B. Sickle cell anemia - Homozygous
C. Sickle cell - Hemoglobin C disease
D. Sickle cell - Thalassemia disease

Onset:

Sickling becomes apparent after four months of age

Symptoms:

A. Weakness
B. Loss of appetite
C. Joint, back and abdominal pain

D. Fever
E. Vomiting
F. Growth retardation

Medical Management:

A. Treat medical emergency of sickle cell crisis
B. Prevent factors contributing to sickle cell crisis: acidosis, hypoxia, dehydration.

Nursing Goals:

A. Explain the disease to family
B. Prevent tissue deoxygenation - see care plan for interventions
C. Promote adequate fluid intake
D. Prevent infection
E. Refer to genetic counselling
F. Provide emotional support
G. Provide relief from pain
H. Promote bonding with infant especially during periods of hospitalization for sickle cell crisis (See Nursing Care Plan for High Risk Infant)

CONGENITAL HEART DEFECTS

Definition:

A. Changes in blood circulation which normally occur in the transition from intrauterine life to extra-uterine life do not occur
B. Malformations of the various cardiac structures usually occurring between 5-8 weeks gestation

Pathophysiology:

A. Increased cardiac workload
B. Pulmonary hypertension
C. Decreased arterial oxygen saturation

Incidence:

8-10:1000 live births

Risk Factors:

A. Maternal rubella, coxsackievirus
B. Poor maternal nutrition
C. Maternal substance abuse
D. Maternal age over 40
E. Maternal insulin-dependent diabetes
F. Maternal ingestions of lithium salts
G. Family history of congenital heart defects
H. Down's Syndrome
I. Is born with other noncardiac anomalies
J. Prematurity
K. Radiation

Onset:

Shortly after birth or during periods of increased demands on the heart (first months of life, adolescence)

Types:

A. Acyanotic: No mixing of oxygenated and unoxygenated blood

   1) Ventricular Septal Defects (VSD) - A hole in the wall between the right and left ventricles

   2) Atrial Septal Defects (ASD) - A hole in the wall between the right and left atria

   3) Patent ductus arteriosus (P.D.S. or P.D.A.) - Failure of the ductus arteriosus (fetally, the ductus arteriosus connects the pulmonary artery to the aorta) to close after birth

   4) Coarctation of aorta - Narrowing of the aorta

5) Pulmonic stenosis - Narrowing at the entrance to the pulmonary artery

6) Aortic stenosis - Narrowing or stricture of the aortic valve

B. Cyanotic defects - Defects where there is no mixing of oxygenated and unoxygenated blood

1) Tetralogy of Fallot (includes)

a. Ventricular septal defect
b. Pulmonic stenosis
c. Overriding aorta
d. Right ventricular hypertrophy

2) Transposition of the great vessels - Pulmonary artery leaves the left ventricle and the aorta leaves the right ventricle

3) Truncus arteriosus - Failure of the pulmonary artery and aorta to develop into separate vessels fetally

4) Total anamalous venous return - No direct communication between the pulmonary veins and the left atrium

5) Tricuspid atresia- Absence of the tricuspid valve

Symptoms:

A. Cyanosis (if a cyanotic defect)
B. Murmurs on auscultation
C. Poor weight gain and growth
D. Easily fatigued especially during feeding
E. Tachycardia
F. Dyspnea, shortness of breath
G. Excessive weight gain
H. Hypertension
I. Clubbing of fingers or toes
J. Classic squatting position

Medical Management:

A. Surgical or pharmacological correction
B. Prevention of complications such as congestive heart failure
C. Family support if prognosis is poor

Nursing Goals:

A. Observe for signs and symptoms of congenital heart disease
B. Assist family and infant adjust to the disease
C. Teach family about disease
D. Assist family in the development of coping strategies for handling the disease symptoms
E. Facilitate grieving and promote bonding
  1) Dying infant, see Nursing Care Plan for the Infant with a Terminal Illness
  2) Loss of a perfect newborn, see Nursing Care Plan for the High Risk Infant

NURSING CARE PLAN - INFANT WITH ANEMIA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Lethargy Poor Eater Poor Growth Patterns Skin color: pale - to waxy pallor Pallor of conjunctiva Abnormal lab findings RBC - Red blood count Hb - Hemoglobin HCT - Hematocrit MCV - Mean corpuscular volume MCHC - Mean corpuscular hemoglobin concentration Reticulocyte count	Activity intolerance related to imbalance between oxygen supply and demand	Parents are able to identify factors in their infant which increase fatigue Reduce factors which increase fatigue Provide adequate nutrients to improve hemoglobin production Prevent infection	1. Refer for confirmatory laboratory testing 2. Teach parents what signs of fatigue to observe for in infants -- weak suck - sleepiness -- irritability -- apathy -- poor growth -- muscle weakness -- Pale, waxy skin color 3. Assist families in planning feeding times which allow for adequate rest 4. Assist families to identify activities which provide infants with stimulation but allow for adequate rest -- rocking -- music -- use of infant seat/front pack 5. Encourage family to anticipate infant's needs and not allow infant to cry for long periods of time 6. Prevent exposure to infection by: a. Washing hands before holding infant or providing infant care b. Restrict visitors with active illness (cough, nasal discharge, vomiting or diarrhea)	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			c. Check temperature. Make sure family has a rectal thermometer, knows how to use and read it	
			d. Notify health care provider when infant shows signs of infection. (Elevated temperature, cough, nasal discharge, vomiting or diarrhea)	
			7. Adequate nutrition	
			a. Vitamins with iron	
			b. Iron fortified formula	
			c. Iron fortified infant cereals	
			d. If finances a problem - Refer to local Women, Infants and Children Program.	

NURSING CARE PLAN - SICKLE CELL ANEMIA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Shortness of breath during feeding/exertion Cyanosis Poor feeding and weight gain Vomiting Constipation Lethargy Crying Fussiness during periods of activity Use of accessory muscles of chest Neck vein distention Decreased bowel sounds Decreased urinary output Atrophy or weakness of extremity muscles	Impaired gas exchange related to the inability of sickled red blood cells to carry oxygen and carbon dioxide	Family is able to: Verbalize the importance of promoting tissue oxygenation Demonstrate the care necessary to promote adequate tissue oxygenation	1. Avoidance of strenuous physical exertion -- Provide frequent rest periods during feeding -- Appropriate utilization of oxygen during feeding, if feeding causes cyanosis -- Do not allow infant to cry for long periods. (Observe during crying for cyanosis) - signs of cyanosis in black infant - blueness in mouth, nailbeds -- As infant develops mobility (around six months of age) observe for respiratory distress (shortness of breath, cyanosis) -- Plan activities which allow for periods of frequent rest -- Front packs for small infants and back packs for older infants are very helpful in providing stimulation and mobility with limited exertion by infant 2. Avoidance of emotional stress -- Do not allow infant to cry for prolonged periods -- Use distraction to discipline older infants	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			3. Prevention of infection: -- Appropriate immunizations -- Wash hands before handling infant -- Limit contact with individuals with known infections (cough, nasal discharge, vomiting, diarrhea, strep infections, chicken pox) -- Encourage adequate nutrition -- Use of infant vitamins -- Be sure parents know how to take rectal temperature and read thermometer -- Notify physician if fever, pallor, pain or other signs of infection 4. Avoid low-oxygen environments -- Do not fly infant in unpressurized airplane -- Avoid taking infant to areas of high altitude (over 2,500 feet above sea level)	
Generalized crying Irritability Restlessness Crying when position is changed (Joint pain is prevalent)	Alterations in comfort: pain related to vaso-occlusive crises.	Family is able to provide pain relief for infant.	1. Provide a quiet environment 2. Give analgesics - Acetaminophen, no aspirin - as ordered. 3. Reposition. 4. Reassure by staying with baby, holding and comforting during episodes of pain.	

NURSING CARE PLAN - SICKLE CELL ANEMIA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Sticky mucous membranes Soft eyeball tension - Eyes appear sunken and dark circles under eyes Dry, cracked lips/skin Nonelastic skin turgor over abdomen Reduced urinary output Intake inadequate for weight and age	Potential fluid volume deficit related to increased blood viscosity caused by the sickle shaped red blood cells, splenic congestion and inconsistent kidney filtration	Family is able to: Explain the cause of fluid volume deficit and how to prevent the deficit Provide infant with adequate fluid volume	1. Teach family about the importance of fluids to prevent sickle cell crisis 2. Weigh infant monthly and calculate fluid intake on basis of infant's weight Table: Water requirements per kg. per 24 hours in milliliters 3 days of age 80-100 ml/kg/24 hours 10 days of age 125-150 ml/kg/24 hours 3 months 140-160 ml/kg/24 hours 6 months 130-135 ml/kg/24 hours 9 months 125-140 ml/kg/24 hours 1 year 125-140 ml/kg/24 hours Formula -- Convert infant's weight from pounds to kilograms to weigh infant on kilogram scale 2.2 pounds = 1 kilogram -- Multiply the number of milliliters by the infant's weight in kilograms -- Convert milliliters to ounces for parents (30 ml=1 oz.) 3. Explain to parents that this fluid amount is the MINIMUM fluid the infant must have every 24 hours 4. Give parents written instructions regarding the amount of fluid the infant must take in.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			5. Offer infant nutritious fluids (such as formula, juices, soup, jello with fruit in it). No products made from cow's milk until 1 year of age.	
			6. Use "special" cup/glass to give infant liquids	
			7. Take advantage of thirsty times such as after awakening	
			8. Offer small, frequent amounts of fluids	
			9. Popsicles may be made of juice. May use frozen pudding or yogurt after 1 year of age, when cow's milk has been introduced into diet.	
			10. Teach parents signs of dehydration a. Weight loss b. Dry mucous membranes c. Dry cracked lips and skin d. Sunken fontanels	
			11. Stress to parents the importance of overheating as a source of fluid loss a. Proper indoor and outdoor clothing b. Avoid excess exposure to sun c. Do not leave child alone in closed car d. Air conditioning in home/car where possible	

NURSING CARE PLAN - SICKLE CELL ANEMIA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Lack of exposure to information about sickle cell anemia Misinterpretation of previous information Cognitive limitation Unfamiliarity with information resources Inaccurate follow-through of instructions Inappropriate or exaggerated behaviors (ex., hostile, hysterical, apathetic, agitated) Statement of misconception Family requests information Family stage of adaptation to disease -- Disbelief -- Denial -- Depression -- Anger -- Awareness -- Acceptance Level of education Ability to read Health care beliefs and practices	Knowledge Deficit: Sickle Cell Anemia related to grief process and Lack of exposure to information about illness.	Family will be able to: Describe sickle cell anemia, causes, factors contributing to the symptoms, the procedures for control of sickle cell anemia and prevention of sickle cell crisis Experience less anxiety related to fear of the unknown, fear of loss of control, misconceptions or previously given information Actively participate in the care of their infant with sickle cell anemia	1. Reduce or eliminate barriers to learning -- Delay teaching until family is ready -- Focus teaching on here and now until family indicates readiness to learn more -- Encourage family members to express feelings about sickle cell anemia -- Tailor teaching to family's stage of acceptance of sickle cell anemia -- Encourage parents to verbalize feelings about the guilt they may feel at having "given" infant the disease -- Refer family for genetic counselling Shodair Genetics Clinic 840 Helena Avenue 442-1980 Helena, MT 59601 2. When family is ready, offer: "A Sickle Cell Home Study Kit for Families" National Association for Sickle Cell Disease, Inc. 3460 Wilshire Blvd., Suite 1012 Los Angeles, CA 90010	

NURSING CARE PLAN - SICKLE CELL ANEMIA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			3. Teach family members the basic infant care necessary for their infant. 4. Give positive reinforcement for attempts at learning and following through.	

NURSING CARE PLAN - CONGENITAL HEART DEFECTS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
History: Onset and duration Symptoms precipitated by what? Symptoms relieved by what? What makes the symptoms worse? Poor feeding, cyanosis during feeding Vomiting Shortness of breath Frequent respiratory infections Current drug therapy Exercise intolerance Heart rate, rhythm, presence of gallops, murmurs Respiratory rate, rhythm depth, presence of cough, rales, wheezing Pulse: Apical, peripheral amplitudes, rate bilateral, Difference between upper and lower Neck veins - Distended, Flat	Alterations in cardiac output: Decreased growth and activity related to (specify the heart pathology)	Family will be able to: Identify factors which increase cardiac workload Describe adaptive techniques needed to provide infant care and meet developmental needs Provide care to infant incorporating special needs of infant	1. Review with parents the procedure in giving Digoxin -- Check dosage - To be sure it is within safe limits Digitalizing 60-80 ug/kg P.O. 40-60 ug/kg I.M. Maintenance 10-20 ug/kg day P.O. This is given in 2 divided doses, 8-12 hours. -- Observe parents taking apical pulse for one full minute -- Withhold medication if apical pulse is less than 90-100 beats per minute and notify physician -- Encourage adequate potassium intake. Use supplement until infant is taking solid foods (bananas, orange juice, apple juice) -- Monitor serum potassium level monthly -- Teach parents signs of digitalis toxicity in infants: bradycardia anorexia, vomiting -- Serum digoxin levels p.r.n. 2. Remind family to avoid extremes of temperatures -- Adequate indoor/outdoor clothing	

NURSING CARE PLAN - CONGENITAL HEART DEFECTS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Skin - Color, Temperature -- Presence of edema -- Pallor, cyanosis			-- Observe infant carefully during periods of extreme heat	
			3. Feeding	
			-- Assure well-balanced diet	
Blood pressure - taken in both the arm and the leg			-- Discourage food with high or added salt content	
Clubbing of fingers or toes			-- Remind parents to read labels carefully for sodium and sodium additives	
			-- Feed infant slowly; burp frequently	
			-- Give small, frequent meals	
			-- If concentrated formula is used, use a large holed nipple	
			-- Introduce solids and spoon feeding early	
			-- Encourage foods high in iron (Iron fortified formula, iron fortified cereal, iron supplements)	
			-- Parents should teach other family members or care givers how to feed infant in order to allow for parent's respite.	
			-- Low sodium formulas - Breast milk - Similac PM 60/40 - S.M.A.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- High calorie supplements which are usually added to formula - Polycrose Powder (Ross Lab) - MCT oil - Moducal Powder	
			-- Provide foods high in potassium: apple juice, Pedialyte, mashed bananas	
			4. Prevent infection	
			-- Avoid contact with persons with known infection (nasal discharge, cough, fever, vomiting, diarrhea)	
			-- Wash hands before caring for infant	
			-- Notify physician of any signs of infection	
			-- Provide for adequate rest	
			5. Recognize signs of complications	
			-- Congestive heart failure - Fatigue - Weakness - Restlessness - Poor eating - Pale, cool extremities - Weak peripheral pulses - Shortness of breath	

NURSING CARE PLAN - CONGENITAL HEART DEFECTS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			- Retractions - Flaring nares - Cyanosis - Wheezing - Moist, grunting respirations - Hoarseness, cough - Distended neck and peripheral veins - Increased jugular venous pressure Drug toxicity Digoxin - Anorexia - Vomiting - Bradycardia (slow heart rate) - Arrythmias - Pulse deficit - Elevated serum Digitalis level - Greater than 3 ng/ml Lasix - Nausea and vomiting - Diarrhea - Ringing in ears - Low potassium - Dermatitis - Postural hypotension Thiazides (Diuril, Hydrodiuril) - Nausea - Dizziness - Numbness, prickling or tingling - Muscle cramps - Low potassium - Dermatitis - Acidosis	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			Aldactone* - Skin rash - Drowsiness - High potassium - Poor muscle coordination * Do not give potassium supplement Dyrenium* - Nausea, vomiting - Diarrhea - Weakness - Headache - Dry mouth - Rash - High potassium *Do not give potassium supplement 6. During dyspneic/cyanotic spells, teach parents to put infant in side-lying, knee-chest position, with head and chest elevated -- Use small pillows to infant's back to keep in side-lying position -- To keep head and chest elevated in crib, place pillow between mattress and springs 7. Reduce infant crying by carrying infant in front pack (ex. Snuggli) and as infant grows older use as a back pack 8. Hematocrit done monthly	

NURSING CARE PLAN - CONGENITAL HEART DEFECTS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			9. Arterial Blood Gases - Done when cyanosis is increasing 10. Prepare family for surgical corrections. R.N. should contact M.D. to find out what corrections are planned and ensure that family is prepared for such procedures as CAT scans, cardiac catheterization	

RESOURCES

THE INFANT WITH PROBLEMS OF PRODUCTION AND CIRCULATION OF BLOOD

1. American Heart Association (214) 750-5300
   7320 Greenville Avenue
   Dallas, Texas 75231

2. American Heart Association - Montana Affiliate 1-800-447-9442
   Professional Building #4, First Avenue, North
   Great Falls, Montana 59401

3. National Association for Sickle Cell Disease, Inc.
   3460 Wilshire Boulevard, Suite 1012
   Los Angeles, California 90010

4. March of Dimes Birth Defects Foundation
   1275 Mamaroneck Avenue
   White Plains, New York 10603

   a. North Central Montana Chapter (406) 453-7071
      101 Central Avenue
      Great Falls, Montana 59401

   b. Southwestern Montana Chapter (406) 442-5018
      5 East 15th Street
      Helena, Montana 59601

   c. Yellowstone Valley Chapter (406) 252-7480
      928 Broadwater Center, Suite 205
      P. O. Box 20842
      Billings, MT 59104

5. Montana State Department of Health and
   Environmental Sciences (406) 444-4740
   Handicapped Children's Services
   Cogswell Building - Capitol Station
   Helena, Montana 59620

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XI. THE INFANT WITH PROBLEMS OF NUTRITION

SHORT BOWEL SYNDROME

Definition:

A condition of malabsorption and malnutrition resulting from substantial loss of small intestine and sometimes some or all of the large intestine. Can be either congenital or surgically initiated.

Pathophysiology:

1. Surgical removal of 50% or more of the small intestine.

2. Type of malabsorption depends on the site of surgical resection.

3. Preservation of the ileocecal valve is associated with improved survival in infants.

4. Malabsorption complications associated with the site of resection:

    a. Proximal resection

        1) Iron deficiency
        2) Foliate deficiency
        3) Hypocalcemia
        4) Hypomagnemia
        5) Hypergastrinemia
        6) Decreased circulating cholecystokinin
        7) Decreased circulating secretin

    b. Distal resection

        1) Vitamin B_{12} deficiency
        2) Bile acid malabsorption
        3) Increased oxalic acid in urine
        4) Insufficient zinc

Incidence: Unknown

Risk Factors:

1. Necrotizing enterocolitis
2. Intestinal atresias
3. Intestinal volvulus

Onset: Following surgical correction

Symptoms:

1. Phase I - One to three months long (hospitalized)

    a. Massive diarrhea
    b. Dehydration
    c. Electrolyte imbalance (esp. sodium and potassium)
    d. Mineral losses (esp. magnesium, calcium and zinc)

2. Phase II - 3-12 months long (generally hospitalized, but due to DRG's may be discharged late in this phase)

   a. Reduction in stool volume
   b. Frequent plateaus in oral intake and weight gain

3. Phase III (home care)

   a. Taking small, frequent oral feedings
   b. May have a Hickman/Broviac catheter for parenteral feedings

Medical Management:

1. Nutritional support to maintain life and growth
2. Medications to correct malabsorption problems
3. Monitoring infant's condition regularly

Nursing Goals:

1. Promote parental attachment throughout prolonged hospitalization (see Nursing Care Plan for High-Risk Infant)
2. Teach parents care necessary for safe administration of medication, care of Hickman/Broviac catheter, and methods of meeting oral nutritional needs
3. Monitor growth and development of infant

CELIAC DISEASE (GLUTEN ENTEROPATHY)

Definition: Inability to digest gluten, a substance found in wheat, rye, oats and barley.

Pathophysiology: Two theories:

1. Inborn error of metabolism
   a. Absence of peptidase
   b. Inability to breakdown gliadin, a protein found in gluten
   c. Build-up of glutamine, which is toxic to epithelial cells of the intestinal villi
   d. Damaged intestinal villi causes malabsorption of fats, proteins, carbohydrates, Vitamins D, K, B_{12} and folic acid and minerals calcium and iron

2. Immunologic theory:
   a. Gliadin acts as an antigen which damages intestinal mucosa cells
   b. Damaged mucosa cells fail to produce peptidase
   c. Lack of peptidase causes malabsorption of fats, proteins, carbohydrates, Vitamins D, K, B_{12} and folic acid and minerals calcium and iron

Incidence: 1:2000

Risk Factors:

1. White racial background
2. Tendency to "run" in families

Onset:

Following the addition of wheat, oats, rye or barley cereals to infant's diet

Symptoms:

1. Failure to gain weight/appetite after a bout of diarrhea
2. Irritability
3. Fussiness
4. Apathy
5. Large, frequent, foul-smelling, frothy stools
6. Peripheral edema
7. Osteomalacia
8. Inadequate blood coagulation (bruising, frequent nose bleeds)
9. Anemia

Medical Management:

1. Testing for celiac disease
2. Low gluten diet

3. Supplemental vitamins, minerals
4. Frequent follow-up on growth

Nursing Goals:

1. Prevention of celiac crisis
2. Teaching parents dietary control
3. Promotion of positive self-concept in infant/child
4. Assist parents in bonding with infant who requires special diet, may not be growing and developing at a normal rate, and may have offensive stools (see Nursing Care Plan for High-Risk Infant)
5. Promotion of optimal growth and development

INTUSSUSCEPTION

Definition: Telescoping of one portion of the intestines into another.

Pathophysiology:

1. Obstruction of the passage of intestinal contents
2. The two walls of intestines rub against one another causing edema, inflammation and diminished blood flow
3. As intussusception continues, necrosis, hemmorrhage, intestinal perforation and peritonitis occur
4. Death can occur if not corrected

Incidence: Unknown

Risk Factors:

1. Male
2. Under two years of age
3. History of cystic fibrosis
4. History of celiac disease
5. More common in spring and autumn

Types:

1. Ileocolic - Ileum telescopes into cecum through ileocecal valve
2. Ileoileal - One part of ileum telescopes into another section of ileum
3. Colocolic - One part of colon telescopes into another section of colon

Onset:

1. 50% of all cases occur between 3 and 12 months of age
2. 45% of rest of cases occur in second year of life

Symptoms:

1. Acute abdominal pain (Infant screaming and drawing knees up to chest) alternating with pain-free periods
2. Vomiting and normal brown stool
3. As illness progresses: Vomiting increases
4. Apathy
5. Red, currant jelly-like stools
6. Abdominal tenderness and distention
7. Sausage-shaped mass in upper right quadrant upon palpation
8. Lower right quadrant feels soft and empty upon palpation
9. Non-classical but common symptoms:
    - Diarrhea
    - Constipation
    - Occassional vomiting
    - Periodic colic

Medical Management:

1. Nonsurgical correction through use of a barium enema (75% effective)
2. Surgical correction of telescoping intestines and resection of any necrosed intestines

Nursing Goals:

1. Prepare parents for surgical and non-surgical medical treatment.
2. Reduce separation anxiety by encouraging rooming-in and/or frequent visitation.

HIRSCHSPRUNG'S DISEASE (CONGENITAL AGANGLIONIC MEGACOLON)

Definition:

Mechanical obstruction caused by inadequate mobility in part of the colon

Pathophysiology:

1. Absence of autonomic parasympathetic ganglion cells of the submucosal and myenteric plexuses
2. Functional defect: Absence of peristalsis causing accumulation of intestinal contents and bowel distention proximal to the defect
3. Failure of internal rectal sphincter to relax

Incidence:

1. 25%-35% of all neonatal obstructions are a result of Hirschsprung's Disease

Risk Factors:

1. Male
2. Family history
3. Down's Syndrome

Types:

1. Rectosigmoid colon
2. Internal sphincter
3. Entire colon

Onset:

1. May appear within 24 hours after birth
2. May appear later in infancy

Symptoms:

1. Poor weight gain and growth
2. Abdominal distention
3. Diarrhea
4. Vomiting

Medical Management:

1. Isotonic enemas
2. Stool softeners
3. Low residue diet
4. Surgical intervention
    a. Removal of aganglionic bowel
    b. Improve functioning of internal sphincter
    c. Temporary colostomies to give bowel chance to heal itself. Closure of colostomies is usually done within a few months to one year.*

Nursing Goals:

1. Gather complete dietary and bowel habits history
2. Assist parents in learning to provide care and manage diet
3. Prepare family for surgical intervention
4. Promote bonding with infant who has problems with feeding and elimination and who may require periods of separation with hospitalization (See Nursing Care Plan for High Risk Infant).

*For infant colostomy care - see Nursing Care Plan for Infant Requiring Ostomy or Special Bowel Care in Section IX: The Infant with Problems of Elimination of Body Waste.

FAILURE-TO-THRIVE
(WITHOUT ORGANIC CAUSE)

DEFINITION:

Infants whose height and/or weight fall below the 5th percentile for their age. No physiological or organic cause can be found for growth retardation.

PATHOPHYSIOLOGY:

Lack of physical growth which is caused by lack of sensory and emotional stimulation.

INCIDENCE:

Unknown.

RISK FACTORS:

1. Family history of abuse, neglect and/or failure-to-thrive.
2. Isolation and social crisis.
3. Inadequate support systems.
4. Physical and mental health problems in parents.
5. Immaturity.
6. Lack of commitment to parenting.
7. Unwanted pregnancy.
8. Financial stress.

ONSET:

Anytime in first year of life.

SYMPTOMS:

1. Weight below 5th percentile.
2. Stiff, rigid, unpliable or limp and floppy.
3. Little or no eye-to-eye contact.
4. Infant doesn't mold to holder's body.
5. History of difficult feeding, vomiting, and depressed appetite.
6. Sleep disturbance.
7. Excessive irritability.
8. Passive, sleepy, lethargic.
9. Does not seek comfort from parent.

MEDICAL MANAGEMENT:

1. Evaluate infant for organic problems which would cause diminished growth.
2. Correct medical problems such as anemia.
3. Referral to community health nurse for home evaluation, treatment and follow up.
4. Hospitalize for severe failure-to-thrive.

NURSING GOALS:

1. Identify families at risk for failure-to-thrive.
2. Assist parents in providing optimum nutrient and feeding environment.
3. Reduce parental anxiety.
4. Teach parents skills necessary for adequate parenting.
5. Refer to community financial and/or social resources.
6. Promote development of parent/infant attachment. (See Nursing Care Plan for High Risk Infant).
7. Refer to SRS if child neglect is suspected.

CLEFT LIP AND CLEFT PALATE

DEFINITION:

Incomplete development of the palate and/or the lip.

PATHOPHYSIOLOGY:

A. Failure of the maxillary processes to fuse to the nasal elevations on the frontal prominence during the sixth week of gestation.

B. Seventh and twelfth weeks of gestation - Delay in the movement of the second lateral palantine processes and/or failure of the tongue to descend into the lower mouth and jaw.

INCIDENCE:

1 per 1,000 live births in whites
2 per 1,000 live births in Japan
1 per 2,500 live births in blacks

TYPES:

A. Cleft lip (CL)
B. Cleft lip and palate (CLP)
C. Cleft in the hard and soft palate (CP)

RISK FACTORS:

A. Cleft lip with/without cleft palate more common in males. Cleft palate alone more common in females.
B. Other congenital anomalies.
C. Family history of cleft palate.

ONSET:

After 12th week of gestation.

SYMPTOMS:

A. Cleft lip.
B. Incomplete fusion of soft and hard palate.

MEDICAL MANAGEMENT:

A. Surgical correction.
B. Participation in health care team.

NURSING GOALS:

1. Teach family to prevent trauma to suture site.
2. Assist family in providing adequate nutritional intake.
3. Facilitate parental acceptance of infant and formation of parent/infant attachment (See Nursing Care Plan for High Risk Infant).
4. Refer to community support agencies.
5. Refer for genetic counselling.
6. Promote normal speech and hearing development.

PHENYLKETONURIA (PKU)

Definition: an inherited disorder in which the liver enzyme phenylalanine hydroxylase is inactive or absent.

Pathophysiology:

1. Autosomal recessive trait

2. Absence of inactivity of the liver enzyme blocks the metabolism of phenylaline to tyrosine. (Tyrosine is used to produce melanine).

3. Phenylalanine accumulates in the blood and if elevations are prolonged, significant and irreversible neurological damage results.

Incidence: One in every 10,000 - 20,000 live births

Risk Factors:

1. White with Northern European or United States ethnic background
2. Family history

Onset:

1. If low phenylalanine diet is begun within three weeks of birth, performance on a standard IQ test is at the same level as non-PKU children.
2. If diet is begun 3-6 weeks after birth, slightly lower IQ's result.

Symptoms:

1. Mental retardation
2. Blond/light brown hair, blue eyes
3. Fair skin subject to eczema
4. Musty odor
5. Failure to thrive
6. Frequent vomiting
7. Irritability
8. Hyperactivity
8. Unpredictable, erratic behavior

Medical Management:

1. Phenylalanine restricted diet

Nursing Goals:

1. Assist family in coping with feelings of grief and guilt associated with a genetic health problem
2. Promote family's development of coping strategies for low phenylalanine diet

3. Cooperate and consult with Registered Dietitian working with the family in monitoring the child's restricted diet.
4. Monitor the growth and development status of infant with PKU
5. Assist the family to find resources for Lofenalac formula, laboratory and finances
6. Remind mothers who have PKU and who are pregnant to maintain low phenylalanine diet during the pregnancy
7. Promote bonding with infant who requires special diet. (See Nursing Care Plan for High Risk Infant).

NURSING CARE PLAN - NUTRITION RELATED PROBLEMS

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Monthly weight and height charted on growth chart Midarm circumference Condition of: Hair Skin Nails Mouth Teeth Developmental self-feeding skills -- Holds own bottle -- Sips from a cup -- Drinks by self from a cup -- Feeds self finger foods -- Eats from a spoon -- Feeds self using a spoon Exact diet history on at least a monthly basis -- What foods -- How much taken -- How much formula taken -- What type of feeding system (breast, Evenflo, Playtex, Nuk cleft lip/palate feeding systems) -- What type of formula -- What is infant doing in regard to self-feeding? -- Other fluids besides formula and breast milk taken?	Alteration in nutrition: less than body requirement related to inefficient intestinal absorption or inadequate social stimulation or inability to ingest adequate amounts of food.	The family is able: Describe the infant's health problem and its relationship to nutritional deficiencies Describe infant's care needs and why they are important Demonstrate care of infant which allows for maximum growth and development	1. Family explains what care of infant involves 2. Observe parents during feeding time -- Do they talk to infant? Do they hold infant during bottle feeding? Is interaction positive and encouraging? -- Is infant positioned with head above stomach and can infant establish eye contact with parent? -- Is older infant allowed to play with food? -- Is infant encouraged in his/her self-feeding efforts? -- Is older infant encouraged to participate in family meal times? 3. Formula for infants -- Portagen/Osmolits - for Short Bowel Syndrome -- Lofenelac or Phenyl-Free for PKU -- Are parents mixing formula according to formula instructions/MD's orders -- If formula is thick - Enlarge nipple hole with a sharp knife -- Hold infant's head above shoulders during feeding -- Refrigerate unused formula for no more than 24°	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Vitamins - What type and how often?			4. If mother wishes to breast feed, encourage her to do so if dietary restrictions permit. A baby with a cleft lip or palate may be able to suck at the breast and should be encouraged to try.	
Financial status of family				
Source of special formulas, parenteral formula, vitamins			5. Review with parents the care of Hickman/Broviac catheter, colostomy care. (See care plan for Child with Ostomy). Include copy of written home care instructions in infant's chart	
Source of equipment such as dressings, colostomy supplies, Kangaroo pump and tubings				
Care routine of supplies, equipment, and infant			6. If child has colostomy, assess skin for irritation/redness, excessive diarrhea, ribbon-like stools, bleeding, constipation	
Activity level of infant				
Knowledge of infant's nutrition needs, perception of infant's health problem			7. Assist family in finding community sources for needed supplies	
Support system to provide infant care as respite for parents			8. For older infants on Low residue diet give parents list of high residue foods to be avoided: -- Whole grain bread, rolls, cereals or products made with whole grains -- Brown rice -- Highly flavored cheeses -- Ice cream/yogurt with fruits/nuts -- Fried eggs -- Tough, fatty, spiced meats and gravies -- Raw or whole cooked vegetables (strained, pureed are OK) -- French fries, potato chips -- Raw fruits -- Raisins, prunes, other dried fruit -- Jams, preserves, marmalade -- Nuts, spices, vinegar, popcorn, olives	
Diagnostic studies - Hemoglobin - Serum albumin - Vitamin levels - Phenylalinine level - X-rays				
Religious dietary restrictions				
Ethnic background				

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			9. Gluten-free diet (high sources of gluten) -- Oats, wheat, barley and rye flours and products -- Bread, cake, cookies, crackers, doughnuts, pies, spagetti, pizza, prepared soups, some processed ice cream, many types of chocolate candy, malted milk, hot dogs, lunch meat, meat gravy, and some prepared hamburgers -- Watch on labels for 'hydrolyzed vegetable protein' because this is a source of gluten -- Remind and support parents that gluten free diet is life-long. Occasional lapses will not cause distress but frequent lapses can cause crisis -- Remind parents to notify any M.D. of celiac disease because anticholinergic drugs can precipitate a crisis 10. Review with parents medications infant is on and their usual administration schedule. -- Make a calendar to write down medications and time given -- Leave a written schedule of medications posted in a prominent place -- Keep all medications locked up 11. For PKU - Sources of phenylalanine to be avoided -- Meats -- Dairy products Cookbook - Schuett, V. ed.: Low protein Cookery for Phenylketonuria, Madison, 1977, University of Wisconsin Press	

RESOURCES

THE INFANT WITH PROBLEMS OF NUTRITION

1. Special Child Health Services
   2023 W. Ogden Avenue
   Chicago, Illinois 60612

2. National Institute of Dental Research
   Westwood Building
   5333 Westbard Avenue
   Bethesda, Maryland 20205

3. Montana Department of Health and Environmental Sciences (406) 444-4740
   Family/MCH Bureau
   Nutrition Services
   Cogswell Building
   Helena, Montana 59620

4. Shodair Genetics Clinic (406) 442-1980
   840 Helena Avenue
   Helena, Montana 59601

5. Local County Extension Services

6. Christine M. Trahms, R.D., M.S.
   Teaching Associate, Division of Genetics
   Department of Pediatrics
   University of Washington
   Seattle, Washington

7. Rita Bradley, R.D. (406) 782-2386
   RTI - Community Nutrition Division
   630 Utah
   P.O. Box 4113
   Butte, Montana 59702

8. Local Hospital and County Health Department Registered Dieticians

9. Handicapped Children's Services
   Montana Department of Health and Environmental Sciences (406) 444-4740
   Family/MCH Bureau
   Cogswell Building
   Helena, Montana 59620

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XII. THE INFANT WITH PROBLEMS OF FLUID & ELECTROLYTE BALANCE

PYLORIC STENOSIS

DEFINITION:

Obstruction at the pyloric sphincter by hypertrophy of the circular muscle of the pylorus.

PATHOPHYSIOLOGY:

A. Enlarged circular muscle of the pylorus
B. Severe narrowing of the pyloric canal between the stomach and the duodenum
C. Thickened muscle
D. Distended stomach

INCIDENCE:

5 of every 1,000 males
1 of every 1,000 females

RISK FACTORS:

A. Male
B. First-born children
C. Family history of pyloric stenosis
D. Occurs most commonly in white infants

ONSET:

4-6 weeks after birth.

SYMPTOMS:

A. Projectile vomiting 4-6 weeks after birth. Vomiting occurs within several hours after feeding and may be intermittent.
B. Weight loss.
C. Stools diminished in size and number.
D. Signs of dehydration present.

MEDICAL MANAGEMENT:

A. Reduction of dehydration.
B. Surgical correction.

NURSING GOALS:

A. Assess for pyloric stenosis in newborns at risk.
B. Prevent vomiting and dehydration.
C. Refer for medical treatment any infants suspected of pyloric stenosis.
D. Teach parents post-operative care and follow-up.
E. Assist parents with bonding while child is hospitalized for surgery

CHRONIC GLOMERULONEPHRITIS

DEFINITION:

Advanced disease of the glomerular filtration system within the Bowman's Capsule of the kidney.

PATHOPHYSIOLOGY:

A. Immunological mechanisms directly attack the kidneys or

B. Accumulation of immune complexes in the glomerular filter or

C. Fibrin deposits from previously damaged glomeruli.

INCIDENCE:

Unknown

RISK FACTORS:

A. History of: Systemic lupus erythematous anaphylactiod (Scholein-Henoch Purpura).

B. Sickle-cell disease.

C. Polyarteritis nodosa.

D. Bacterial endocarditis.

E. Prolonged bacteremia.

TYPES:

A. Persistent glomerulonephritis -- No specific histologic picture but fail to demonstrate expected recovery from acute phase.

B. Chronic glomerulonephritis -- Advanced glomerular disease.

C. Rapidly progressive glomerulonephritis -- Severe acute onset resembling acute poststreptococcal glomerulonephritis but cause rapid degeneration of kidney function within 6-12 months.

ONSET:

Damage can occur anytime in infancy/childhood but symptoms develop most commonly during adolescence.

SYMPTOMS:

Hypertension, edema, proteinuria, cardiac failure, dyspnea, anemia, osteodystrophy.

LAB FINDINGS:

Elevated BUN, creatinine, uric acid, phosphorus. Decreased sodium and calcium.

MEDICAL MANAGEMENT:

A. Symptom treatment.

B. Referral to tertiary care facility specializing in renal disease.

NURSING GOALS:

A. Prevent dehydration.

B. Monitor fluid balance.

C. Prevent infection and hypertension.

D. Minimize catabolism.

E. Teach family signs of electrolyte elevation and nitrogenous waste.

F. Support family.

G. Promote normal growth and development.

H. Promote bonding with infant who has a long-term medical problem. (See Nursing Care Plan for High Risk Infant).

NURSING CARE PLAN - PROBLEMS IN FLUID AND ELECTROLYTE BALANCE

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
History of: -- Decreased urinary output -- Diarrhea -- High solute tube feedings (Hyperalimentation) -- Kidney disease -- Medications, Diurectics Objective data Daily weight Increased pulse rate (Norms for infant to 1 yr. 120-160) Increased respiratory rate (Norms for infant to 1 yr. 30-60) Decreased blood pressure (Norms 90/61 ± 25/20) Skin turgor Dry lips and gums Furrowed/dry tongue Skin Color (Pale/flushed) Depressed fontanels Sunken eyeballs Urine output varied Color (amber, very dark) Less intake than output Neck veins flatten out when infant is lying flat Lab Data -- Hemaglobin/Hematocrit -- Electrolytes -- Urinalysis (especially specific gravity) -- BUN -- Creatinine	Fluid Volume Deficit related to: inability of the kidney to concentrate urine or vomiting	Infant takes in fluid to maintain metabolism Parents can describe the importance of fluids especially during increased stress/illness/heat. Parents demonstrate the ability to maintain appropriate fluid intake. Parents able to describe the signs and symptoms of dehydration and/or fluid volume excess (edema).	1. Review with parents important signs and symptoms which they should notify doctor. -- Poor feeding -- Vomiting -- Failure to gain weight -- Excessive thirst -- Frequent urination -- Screaming/straining on urination -- Foul-smelling urine -- Pallor -- Fever -- Persistent diaper rash -- Convulsions -- Dehydration -- Enlarged kidneys or bladder 2. Review with parents foods which are high in Sodium. -- Cow's milk -- Cheese -- Salted crackers, chips, etc. -- Tomatoes -- Prepared meats (lunch meat, ham, etc.) -- Catsup 3. Remind parents to not purchase baby food with salt or sodium added. 4. Review with parents, foods which are high in Potassium. -- Apple Juice -- Bananas -- Oranges -- Broccoli 5. Refer for nutrition evaluation - Most infants are on a protein limitation to essential amino acids needed for growth.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			6. Review foods rich in iron and folic acid. Review with parents the importance of giving vitamin supplements.	
			7. Allow infant to set own pace for activity, sleep and rest.	
			8. Formula is usually a low protein, low electrolyte formula with caloric supplements. Cow's milk is restricted.	
			9. Medications	
			-- Aluminum hydroxide gel - Binds phosphorus in intestines and prevents absorption.	
			-- Calcium supplement (calcium gluconate, calcium carbonate, calcium lactate).	
			-- Shohl's solution (potassium and sodium citrate) to correct acidosis.	
			-- Vitamin D or Dehydrotachysterol.	
			-- Folic acid and iron supplement.	
			-- Hydrochlorothiazide/furosemide.	
			-- Severe hypertension - reserpine, hydralazine, and/or methydopa.	

NURSING CARE PLAN - PROBLEMS IN FLUID AND ELECTROLYTE BALANCE

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			10. Calculate fluid needs on the basis of weight and age. 10 days 80 - 100 cc/kg/24° 3 months 140 - 160 cc/kg/24° 6 months 130 - 135 cc/kg/24° 9 months 125 - 145 cc/kg/24° 1 year 120 - 133 cc/kg/24° (Vaugh and Nelson - textbook of Pediatrics, ED 11, Saunders, 1979) Change cc's into ounces so parents can measure fluids using household measuring tools. 30 cc = 1 ounce 11. Assist parents in organizing fluid and medication record. 12. Prevent infection -- Wash hands before handling infant -- Avoid contact with persons with colds, sore throats, vomiting or diarrhea -- Administer prescribed antibiotics at the first sign of infection 13. Maintain as normal a life as possible. -- Provide appropriate developmental stimulation -- Assist parents in finding acceptable respite care 14. Refer parents to financial resources as appropriate.	

NURSING CARE PLAN - PROBLEMS IN FLUID AND ELECTROLYTE BALANCE

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			15. Prevent vomiting -- Give small frequent feedings; feed slowly -- Bubble frequently before, during and after feedings -- Position in high - Fowler's (use an infant seat) and slightly on right side after feedings -- Handle minimally and gently after feedings -- Add rice cereal to formula to provide thicker consistency	
			16. Change diapers immediately when wet or soiled.	
			17. Begin treatment immediately of reddened diaper areas. -- Avoid use of plastic pants where possible -- Expose buttocks to air 3-4 times/day for 15 minutes -- Warm bath daily will speed healing -- Use diaper cream as directed -- Hydrocortisone creams may be helpful but must be used with caution -- If using cloth diapers - be sure detergent is completely rinsed out	

RESOURCES

THE INFANT WITH PROBLEMS OF FLUID & ELECTROLYTE BALANCE

1. National Kidney Foundation (212) 889-2210
   2 Park Avenue, Room 908
   New York, New York 10016

2. National Information Center (703) 528-8480
   for Handicapped Youth and Children
   155 Wilson Boulevard
   Rosslyn, Virginia 22209

3. Shodair Lay Lending Library (406) 442-1980
   840 Helena Avenue
   Helena, Montana 59601

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XIII. THE INFANT WITH PROBLEMS OF ELIMINATION OF BODY WASTE

OBSTRUCTIVE UROPATHY

DEFINITION:

Structural and/or functional abnormalities of the urinary system which causes obstructions to the usual flow of urine and back-up in the urinary system.

PATHOPHYSIOLOGY:

1. Back-up of urine causes collection of urine in renal pelvis.

2. Urine collection in kidney causes damage to nephrons.

3. Urinary stasis provides growth medium for bacteria which further damages the nephrons.

INCIDENCE:

RISK FACTORS:

1. Female

TYPES:

Sites for urinary tract obstruction:

1. Ureteropelvic Valves
2. Renal Valve
3. Posterior Vesicoureteral Valves
4. Posterior Vesicoureteral Valves
5. Urethra

ONSET:

Within six months of birth.

SYMPTOMS:

1. Recurrent urinary tract infections.

2. May have low set ears. (Top of ear below imaginary straight line drawn from outer canthus of eye to ear).

3. Abnormal I.V.P. or voiding cystourethrogram (V.C.U.G.)

MEDICAL MANAGEMENT:

1. Treatment of urinary tract infection.

2. Surgical correction of abnormality as soon as possible.

NURSING GOALS:

1. Teach parents signs and symptoms of urinary tract infections.
2. Prepare family for X-ray and surgical procedures.
3. Teach parents how to prevent urinary tract infections.
4. Assist family in maintaining integrity and positive self-concept during infant's hospitalization for surgery.
5. Teach parents post-surgical care.
6. Promote bonding with infant who requires special care procedures (See Nursing Care Plan for High Risk Infant).

BOWEL ATRESIA

DEFINITION:

Structural abnormalities in the bowel and rectum which impair or inhibit the passage of stool.

PATHOPHYSIOLOGY:

Impaired development of the bowel and rectum at the seventh to eighth week of gestation.

INCIDENCE:

One in 5000 births.

RISK FACTORS:

1. May also have other anomalies of the genitourinary tract, heart and/or esophagus.

TYPES:

1. Congenital anal stenosis - Narrowing of anus.
2. Anal agenesis - Absent anal opening.
3. Anal membrane atresia.
4. Rectal atresia.
5. Rectoperitoneal fistula - Opening from rectum on perineal floor.
6. Rectovaginal fistula - Opening from rectum into vagina.

ONSET:

Anytime in first year of life.

SYMPTOMS:

1. History of difficult defecation.
2. Abdominal distention.
3. Ribbon-like stools.
4. Meconium or stool in urine/vagina.
5. Failure to pass a meconium stool after birth.
6. Inability to pass thermometers into rectum following birth.

MEDICAL MANAGEMENT:

1. Stenosis may be treated by manual dilations done at first by M.D. and repeated at home by parents.
2. Anaplasty.
3. Colostomy for more serious atresias.

NURSING GOALS:

1. Review procedures for manual dilations by parents.
2. Review with parents the procedures for perineal care in anoplasty.
3. Teach parents care of an ostomy.
4. Promote infant self-concept by assisting parents with grieving, the loss of a perfect newborn, and bonding. (See Nursing Care Plan for High Risk Infant).

NECROTIZING ENTEROCOLITIS (N.E.C.)

DEFINITION:

Damage to mucosal cells lining bowel wall which allows intestinal bacteria and enzymes to destroy the thin bowel wall.

PATHOPHYSIOLOGY:

1. Anoxia causes blood to be shunted away from bowel.
2. The vasoconstriction causes severe reduction of blood supply to mucous producing cells lining the bowel.
3. The mucous cells die and the bowel wall is attacked by bacteria and enzymes.

INCIDENCE: Varies from one NICU to another.

RISK FACTORS:

1. Prematurity.
2. Birth hypoxia.
3. Feedings of hypertonic formula enterically.
4. Early initiation of orogastric feedings in very premature infants.

ONSET:

Shortly after birth.

SYMPTOMS:

1. Lethargy.
2. Distended (often shiny) abdomen.
3. Blood in stools and/or gastric contents.
4. Absence of bowel sounds.
5. Respiratory distress.

MEDICAL MANAGEMENT:

1. Discontinuation of oral feedings, nasogastric suction, systemic antibiotics.
2. Moderate damage to intestinal walls - Surgical resection and anastomosis.

3. Severe damage to intestinal walls - Establishment of ileostomy or colostomy.

NURSING GOALS:

1. Teach family care of ileostomy or colostomy.
2. Support parents in care of infant.
3. Teach family nutritional needs of infant.
4. Promote bonding with baby who has an ostomy. (See Nursing Care Plan for High Risk Infant).

NURSING CARE PLAN - OBSTRUCTIVE UROPATHY

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Frequent urinary tract infections -- Leukocytes in urine -- Blood in urine -- Protein in urine -- Abdominal/flank tenderness -- Anorexia -- Unexplained fever and malaise	Alteration in elimination: urinary tract related to back up and stasis of urine in urinary tract.	Parents are able to describe symptoms of urinary tract infections. Parents are able to describe methods of preventing urinary tract infections. Parents demonstrate methods of preventing urinary tract infections. Parents are able to describe surgical correction of the obstructive uropathy. Parents are able to demonstrate care of infant post-surgically.	1. Review with parents signs and symptoms of urinary tract infection in infants. -- Frequent or infrequent diaper changes. -- Constant squirming or irritability. -- Fishy, unpleasant odor. -- Straining when trying to urinate. -- Crying/fussing during urination. -- Dribbling small amounts of urine frequently. -- Fever, chills. -- Vomiting. -- Seizures. -- Poor feeding. 2. Discuss methods of preventing urinary tract infections. -- Wipe infant from front to back after stools. -- Clean in all skin folds after stools. -- Avoid tub baths - When infant is very young, bathe in small amount of warm water (that isn't deep enough to flow into urethra or vagina) can be given. As soon as infant is sitting and/or standing, give showers.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Do not use bubble baths or water softeners. -- Avoid tight clothing and diapers. -- Check for vaginitis or pin worms, especially if infant scratches between legs. -- Encourage adequate fluid intake. 10 days of age 125-150 ml/kg/24° 3 months 140-160 ml/kg/24° 6 months 130-135 ml/kg/24° 9 months 125-145 ml/kg/24° 12 months 120-135 ml/kg/24° -- Give 8 ounces of cranberry/apple juice daily. -- Notify M.D. if parents suspect a urinary tract infection. -- Give prophylactic antibiotics as ordered. 3. Review with parents procedures for giving medications. Medications usually used to treat urinary tract infections. (May be given prophylactically as well). -- Ampicillin -- Amoxicillin -- Sulfonamides *Not used in infants under 2 months of age. -- Furadantin *Not used in infants under 3 months of age.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			4. Prepare parents for diagnostic procedures. -- Call X-ray Dept. where procedure is being done to find out about preparations and routine for doing the procedure. -- Share your findings with parents. -- Procedures usually done: Clean catch urine specimens 1. Clean perineum with a betadine pad, wiping from front to back only once with each pad. Do this at least two times. Wipe off area with sterile water. 2. Apply a sterile wee bag to the perineum. 3. Remove the bag immediately after voiding and take to the laboratory within 20-30 minutes. 4. Do not give large amounts of fluids to encourage urinating. This dilutes the urine specimen. -- Intravenous Pyelogram (I.V.P.) -- Voiding Cystourethrogram (V.C.U.G.) 5. Questions parents should ask surgeon: -- At what age is surgical correction done?	

NURSING CARE PLAN - OBSTRUCTIVE UROPATHY

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- How long will infant be hospitalized?	
			-- Will infant have ureter tubes? What do they do? How long approximately are they in place?	
			-- Will infant have a suprapubic catheter? What does it do? Approximately how long will it be in place?	
			-- When infant is discharged, what kind of care will parents have to do? (e.g., dressing changes, lab specimens, medications, etc.)	
			6. Clarify with parents any questions/ misunderstandings they have about the procedure.	
			7. Assist parents in any arrangements needed for home care of infant after surgery.	
			8. Review with parents aspects of home-care following surgery.	
			-- Dressing change	
			-- Signs and symptoms of infection -- urinary tract -- surgical site	
			-- Fluid requirements	
			-- How to obtain urine specimens	
			-- Administration of medications	
			-- Appropriate hygiene measures to prevent urinary tract infection	

NURSING CARE PLAN - INFANT REQUIRING OSTOMY AND/OR SPECIAL BOWEL CARE

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
History of difficult defecation -- Abdominal distention (abdomen may be shiny) -- Ribbon-like stools -- Blood in stools and/or gastric contents -- Meconium/stool in urine/vagina -- Vomiting (smells like fecal material) -- Lethargy -- Absence of bowel sounds -- Poor feeding -- Water-loss stool or explosive diarrhea -- Bile stained gastric contents	Alteration in bowel elimination related to structural and/or functional abnormalities in the bowel.	Parents are able to describe procedures for providing bowel care to infant. Parents are able to demonstrate bowel care for infant. Parents are able to verbalize their feelings and concerns about the special needs of their infants.	1. Review with parents procedure for finger dilation of anus. (Have parents explain the procedure which M.D. wants them to use.) -- Be sure fingernails are clipped short. -- Use water-soluable lubricant (K-Y jelly) instead of Petroleum based product. -- Use finger cot or non-sterile exam glove. 2. Review with parents procedures for meticulous perineal care. -- Clean diaper area with soap and warm water thoroughly after each diaper change. -- With diarrheal stools, may be most advantageous to wash infant's diaper area under running water in tub or sink. This is more efficient in removing stool and less abrasive than washcloth if area is already irritated. -- Change diaper immediately when wet or soiled. -- Do not use plastic pants until anoplasty is healed. -- Allow infant's bottom to be exposed to air 15-20 minutes 3-4 times a day. 3. Ostomy care (Ostomy is often temporary in infants and may be revised when the child is older).	

NURSING CARE PLAN - INFANT REQUIRING OSTOMY AND/OR SPECIAL BOWEL CARE

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			Non-appliance method (Sigmoid colostomy) a. Assemble all necessary supplies. -- Clean cloth diaper for use as an abdominal binder. (Old infant "belly binders" can be used). -- Absorbent nonsterile surgical pads, Toppers or Chux or facial tissues. -- Karaya gum powder. -- Diaper rash ointment (Desitin, Diaperene, Perianal Cream, Moisture Barrier Ointment) or zinc oxide. -- Two non-abrasive washcloths - one wet and one dry. -- Basin of water. -- Plastic container with lid (to hold Karaya powder and ointment). -- Stirring stick (Popsicle sticks work well). -- Plastic bag to hold garbage. -- Paper tape or safety pins for securing the binder. b. Wash hands. c. Mix Karaya powder and diaper ointment one-to-one in plastic container with lid. Label container.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			d. Remove and dispose of infant's soiled dressings. e. Dab or pat the skin around the stoma clean with warm, wet washcloth. f. Carefully examine the stoma and surrounding skin. (It should be reddish-pink like the inside of infants mouth). There should be no bleeding/skin breakdown. g. Cover area around stoma (2-3 inches) with Karaya powder and ointment paste. h. Cover with one or two absorbent pads. Hold pads in place while wrapping diaper/binder. Tape or pin diaper/binder securely. DO NOT put tape on infant's skin. i. Check stoma site every diaper change and repeat above process as needed. j. In case of persistent excoriation, use a liquid skin sealant (Skin Prep or Protective Barrier Film) before applying paste. Appliance Method a. Gather equipment. -- Basin/bowl or warm water. -- Two nonabrasive washcloths - one wet and one dry.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Plastic disposal bag (plastic grocery bags work well)	
			-- One inch paper tape.	
			-- Liquid skin sealant (Skin Prep or Protective Skin Barrier).	
			-- Scissors	
			-- Peristomal covering (Stomahesive)	
			-- Small rubber band	
			-- 20 cc. syringe	
			-- Adhesive remove (Detachol)	
			-- Plain prophylactic condom or an external male catheter and catheter plug (small size Uro-San is soft and easy to plug and empty)	
			b. Wash hands	
			c. Construct an appliance pattern.	
			-- Use a 3x5 index card	
			-- Cut a circle 2-3 inches in diameter. A glass 2-3 inches in diameter can be used to draw the circle.	
			-- Cut a small hole ¼ inch in diameter in center.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Enlarge hole until it fits over stoma without touching it.	
			-- Enlarge pattern as infant's growth dictates.	
			d. Using pattern, cut two discs of Stomahesive.	
			e. Unroll a condom or catheter and pull the closed end of the condom/catheter through one disc from the side with the paper backing to the shiny side.	
			f. Leave ½ inch or more of condom on the paper side to prevent leakage.	
			g. Remove paper backing from disc. Sandwich the margin or condom/catheter between the shiny side of the second disc and the adhesive side of the first disc. Be sure the paper backing on the second disc is still on.	
			h. Clean the skin thoroughly with a mild, hypo-allergenic fat free soap (Ivory, Neutrogena).	
			i. Rinse and pat dry.	
			j. Apply a thin coat of liquid skin sealant to skin around stoma. Do not get any of the liquid skin sealant on stoma. Cover skin area ½ inch larger than stomahesive pattern.	

NURSING CARE PLAN - INFANT REQUIRING OSTOMY AND/OR SPECIAL BOWEL CARE

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			k. Let skin sealant dry.	
			l. Remove paper backing from appliance. Place appliance on skin around stoma.	
			m. Cut four strips of one inch paper tape 3-4 inches long.	
			n. Frame the adhesive by placing the tape half on the disc and half on the skin.	
			o. Write date of application on tape.	
			p. If condom is used, snip off the closed end of the condom. Fold condom back on itself about ½ inch and bind tightly with a small rubber band. If catheter is used, close open end with catheter plug.	
			q. Tuck appliance inside the diaper, making sure nothing pulls on the appliance.	
			r. Check and empty appliance as often as diaper is changed.	
			s. To empty, remove plug/rubber band and drain.	
			t. To clean appliance, use 20 cc syringe to flush bag. Use a first rinse of warm, soapy water and a second rinse of clear, tepid water.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			u. To remove appliance, use a solvent such as Detachol. Rinse all solvent from skin with soap and water. 3. Refer family to enterostomal therapist, where available.	
Excoriation -- Red -- Open skin break -- Bleeding	Alteration in skin integrity related to effluent coming in contact with skin, or poor/inconsistent stoma care or presence of bacteria/fungus or allergy.	Parents are able to describe methods of preventing skin problems. Parents are able to demonstrate skin care interventions.	1. Excoriation -- Change appliance method to non-appliance or vice versa. -- If nonappliance method is used, apply a stomahesive ring disc to cover excoriation. Cut a hole in stoma hesive for stoma. Leave ring disc in place until the seal begins to loosen. Replace if excoriation is not healed. Continue until healing is complete. -- If excoriation develops from effluent running down infants side, prop infant on other side for longer periods of time. Expose excoriation to sunlight and air for 30 minutes three to four times per day until healed. 2. Fungus -- Parents notify M.D. for prescription for antifungal cream. Monostat Cream Nystatin Powder Micatin Ointment	

NURSING CARE PLAN - INFANT REQUIRING OSTOMY AND/OR SPECIAL BOWEL CARE

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			3. Allergy -- Identify product -- Use a different product -- Use intervention above for treating excoriations -- Apply hydrocortisone cream to affected area 4. Bathe infant whenever appliance is changed.	

RESOURCES

THE INFANT WITH PROBLEMS OF ELIMINATION OF BODY WASTE

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THE INFANT WITH PROBLEMS OF ELIMINATION OF BODY WASTE

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XIV. THE INFANT WITH PROBLEMS OF MOBILITY

WERDNIG-HOFFMAN PARALYSIS
(INFANTILE SPINAL MUSCULAR ATROPHY)

DEFINITION:

Rare, hereditary disorder which interfers with neurological stimulation to arms, legs and intercostal muscles.

PATHOPHYSIOLOGY:

A. Recessive trait
B. Atrophy of anterior horn cells in spinal cord
C. Atrophy of motor nuclei in brain stem
D. Secondary atrophy of motor nerve roots and muscles

RISK FACTORS:

A. Family history

ONSET:

A. Prior to birth or
B. Before age two years

SYMPTOMS:

A. Weakness and hypotonia of proximal and distal limbs
B. Weakness and hypotonia of intercostal and bulbar muscles
C. Paradoxical breathing with inward movement of chest on inspiration
D. Absent tendor reflexes
E. Late stages - Swallowing becomes impossible
F. Death before age 2 due to respiratory failure and/or aspiration
G. Normal mental development

MEDICAL MANAGEMENT:

A. Supportive care to infant and family
B. Treatment of secondary pneumonia

NURSING GOALS:

A. Support family in anticipatory grieving
B. Teach parents infant care (Range of motion, skin care, positioning during feeding, sleep and percussion and postural drainage)
C. Provide age appropriate developmental activities

*For Care Plan - See Infant with Potentially Terminal Illness.

CONGENITAL HIP DYSPLASIA

DEFINITION: Hip malformations which are present at birth.

PATHOPHYSIOLOGY:

A. Acetabular dysplasia (preluxation)

   1) Oblique and shallow acetabular roof
   2) Intact cartilaginous roof
   3) Head of femur in acetabulum

B. Subluxation (most common dysplasia)

   1) Incomplete dyslocation of femur in acetabulum
   2) Stretched capsule and ligaments
   3) Flattened socket

D. Dislocation

   1) Femur loses complete contact with acetabulum
   2) Femur displaced posteriorly
   3) Ligamentum teres elongated and taut

INCIDENCE:

A. One per 500-1,000 births
B. Commonly associated with other conditions

RISK FACTORS:

A. Female (7 females to 1 male)
B. Family history of congenital hip dysplasia
C. American Indian, Eskimo
D. Ethnic cultures which tightly wrap or swaddle infants
E. Breech presentations
F. Cesarean deliveries

SYMPTOMS:

A. Asymmetry of gluteal and thigh folds
B. Limited hip abduction
C. Apparent shortening of femur
D. Ortolanti click if infant is under four weeks of age

MEDICAL MANAGEMENT:

A. Devices - Keep hip/s in full abduction

   1) Double cloth diapers
   2) Plastic, metal or leather devices (Pavlik harness)
   3) Frejka pillow splint
   4) Hip spica cast
   5) Last resort - surgery

B. Surgical correction rarely done in first year of life

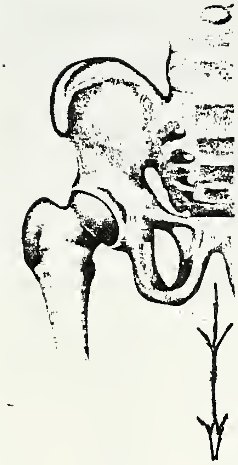
NURSING GOALS:

A. Limit permanent deformities
B. Prevent complications associated with treatment such as skin breakdown, impaired circulation, contractures, impaired growth and development
C. Assist parents in the development of coping strategies
D. Assist parents in bonding with baby in cast, splint, or other device.

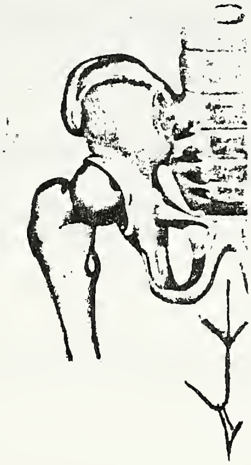
CONGENITAL ORTHOPEDIC ANOMALIES

No. 15 of a series
Nursing Education Aids
Ross Laboratories, Columbus, Ohio 43216

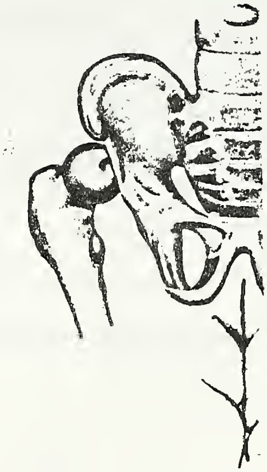
DISLOCATION OF THE HIP



Normal

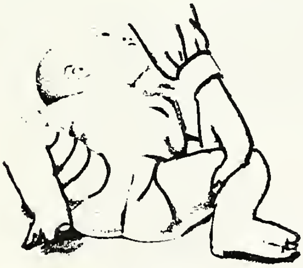


Subluxated

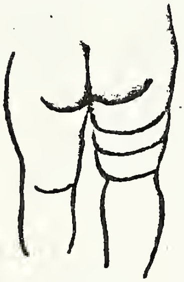


Dislocated

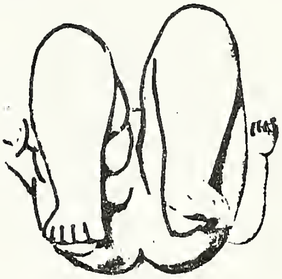
EARLY SIGNS (Dislocation of Right Hip)



Limitation
of Abduction

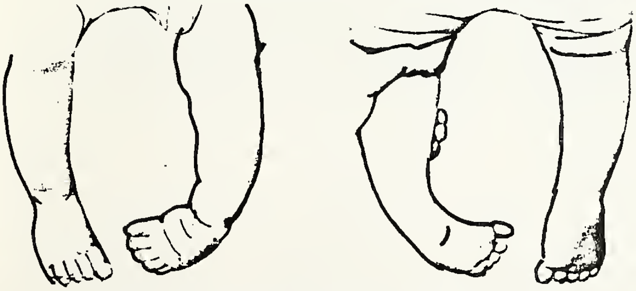


Asymmetry of Skin Folds
Prominence of Trochanter

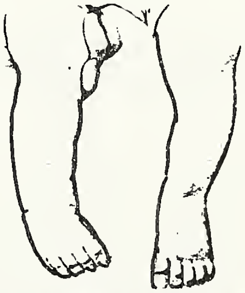


Shortening
of Femur

FOOT ANOMALIES



Unilateral Clubfoot (Talipes Equinovarus)



Unilateral Metatarsus Varus

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OSTEOGENESIS IMPERFECTA

DEFINITION: Rare, hereditary disorder characterized by fragile bones.

PATHOPHYSIOLOGY:

A. Autosomal - dominant trait
B. Inadequate bone cell development to replace normal loss of bone tissue causing fragile bones
C. Abnormal modeling of skull, long bones and low spine
D. Serum alkaline phosphatase is elevated

TYPES AND SYMPTOMS:

A. Type I - Osteoporosis, bone fragility, blue sclerae, presenile conductive hearing loss, spontaneous improvement in puberty
B. Type II - Low birth weight, crumpled bones, thin, fragile skin. 50% die before birth
C. Type III - Severe bone fragility, multiple fractures at birth
D. Type IV - Sclerae bluish at birth with less blue as infant gets older. Variable age of onset of bone fractures. Improves in puberty.

INCIDENCE:

A. Type I - 1 per 30,000 live births
B. Type II - 1 per 60,000 live births
C. Type III - Unknown
D. Type IV - Unknown

RISK FACTORS:

A. Family history

MEDICAL MANAGEMENT:

A. Supportive care to prevent fractures
B. Treatment of fractures

NURSING GOALS:

1. Refer parents for genetic counseling
2. Provide information and support to parents
3. Teach parents care techniques to prevent fractures
4. Assist parents in bonding with child who requires specialized continuous care. (See Nursing Care Plan for High Risk Infant).

NURSING CARE PLAN - CONGENITAL HIP DYSPLASIA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Family history of: -- congenital hip dislocation -- osteogenesis imperfecta -- "floppy" babies Pain - fussy baby -- Protecting a limb by not using it -- Withdrawal from touch of affected limb -- Motor function Strong Weak Absent Right arm Right leg Left arm Left leg Congenital hip dysplasia -- Gluteal folds -- Leg length -- Limited hip abduction -- Ortolanti click if infant is under 4 weeks of age	Impaired physical mobility related to restrictive devices. Impaired growth and development related to immobility. Impaired skin integrity related to immobility, corrective devices.	Parents able to describe the type of problem their infant has Parents able to describe care for special needs of infant Parents able to demonstrate care for special needs of infant Parents able to verbalize frustration, anxiety, guilt	1. Review with parents procedure for doing range of motion (R.O.M.) -- Support limbs above and below joints -- Do not go beyond point of muscular resistance or normal range of that particular joint -- Gentle massage before R.O.M. will often relax muscles -- As infant gets older, include resistance in R.O.M. -- Never do for an infant what he can do for her/himself -- Should be done 2-3 times per day 2. Where physical therapy is ordered, assist parents with transportation, financial aid and resources 3. Change infant's position every hour during the day 4. Assess skin every 8 hours for pressure areas. Check especially under corrective devices. Notify M.D. or corrective devices manufacturer if reddened areas occur 5. Assist parents in ways of maintaining proper body alignment -- Pillows -- Firm, supportive mattress	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			6. As infant is developmentally ready, provide means of mobility appropriate to infant's condition. Example: Infant walker/creeper.	
			7. Refer parents for genetic counseling, if not done previously.	
			8. Care for infant in hip spica cast.	
			-- Use disposable diapers. Petal cast around perineum using tape or op-site.	
			-- Assess skin around cast edges for redness, blisters, abrasions daily.	
			-- Sleeping - use foam wedge to elevate head or place infant on abdomen.	
			-- Feeding - use Unbroller stroller for feeding. "Sassy seat" may also work on strong table	
			-- Playing - put infant on floor or abdomen to give mobility, use a mechanic creeper or crawl-along.	
			9. Pavlik Harness	
			-- Check skin daily under harness for redness, blisters	
			-- Use disposable diapers which have elasticized legs	
			-- Only remove harness under doctor recommendations	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			10. Home Traction -- Bradford frame is used -- Assess toes for warmth, color, capillary blanching -- Infant placed on back with hips flexed 30-45° -- Check weights - must be free -- Rewrap ace bandages every four hours while awake -- May be out of traction for up to 4 hours every 24 hours -- Provide large amount of stimulation	
Parents' willingness to hold baby despite barrier of corrective devices.	Alterations in Parenting: Bonding related to child's abnormality, corrective devices.	Parents provide child with love, affection, and stimulation.	1. Use methods described above to provide more mobility in maintaining parent/baby contact.	
Parents' provision for moving baby from room to room along with them -- maintaining physical contact			2. Encourage parents to hold child on lap and encourage breastfeeding if this is what mother desires. Use pillows, blanket rolls, etc. to position child in cast or splint while being held.	
Parents' efforts to talk with baby, sing, play with her, cuddle, and rock. Maintenance of eye contact. Response to baby's needs when crying.			3. Discuss with parents: -- How to play with baby -- Importance of responding to baby's cries. -- How to provide extra auditory, visual, and tactile stimulation to help make up for lack of mobility.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
Parents' willingness to take baby out of the house, have friends in to visit.			-- Need for respite care. Assist in finding sitters or care givers so that parents can get away.	
Parents' refer to baby by name.			4. Role-play potentially awkward situations parents may encounter in public in order to help parents cope with questions, stares, and negative reactions to child.	
Parents' ability to provide normal infant care as well as meeting special needs of infant with dislocated hips			5. Show interest in baby, commenting on what she is doing, how she looks. Stresss the normal things about her appearance and and activities. Comment on her beautiful face, eyes, skin, hair, etc.	
			6. Support parents in learning normal infant care, as well as special care needs of infant.	
			7. Give parents positive reinforcement for the care that they are providing.	

NURSING CARE PLAN - OSTEOGENESIS IMPERFECTA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed

Family history osteogenesis imperfecta
-- Low birth weight
-- Evidence of intrauterine fractures
-- Bone fragility
-- Sclera - blue color
-- Conductive hearing loss
-- Triangular shaped face with pointed nose and wide forehead
-- Prone to bruising
-- Skin tends to be warm and moist to touch
-- Pain
  -- Fussy Baby
  -- Protecting a limb by not using it
  -- Withdrawal of affected limb from touch
-- Motor function
Strong Weak Absent
Right Arm
Right Leg
Left Arm
Left Leg
-- Muscular Atrophy
Midarm Circumference
Thigh Circumference
	Impaired physical mobility related to extreme fragility of bone tissue.	Parents are able to verbalize care of infant with osteogenesis imperfecta.
		Parents able to demonstrate care of infant using special techniques.
		Parents are able to verbalize concerns and anxiety about caring for infant.
		Parents provide child with love, affection, and stimulation.
			1. Positioning
			-- Rest on softly padded mattress and/or sheepskin.
			-- Change position every two hours while awake. Support proper alignment with towel rolls and sandbags.
			-- If infant tolerates prone position, placing a small foam pad under chest can encourage use of neck and back muscles.
			-- Make all movements with infant slow, gentle and methodical.
			-- Explain to infant what you are going to do.
			-- When lifting infant, place on hand supporting back and head and other hand supporting front of trunk.
			-- Well padded infant seat can be used.
			2. Diapering
			-- Place hand under buttocks and gently lift buttocks and remove diaper and place a clean one on.
			-- Do NOT lift infant by ankles.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			-- Disposable diapers may be more comfortable.	
			3. Bathing	
			-- Bathe infant on a sponge pad or well padded plastic tub.	
			-- Fill tub enough so infant can lie on back in tub.	
			-- Warm water helps reduce pain and swelling of fractures.	
			-- Dry infant very gently.	
			4. Clothing	
			-- Light weight cotton clothing.	
			-- All openings (neck, armholes) should be wide, easily put on and removed.	
			-- Avoid elastic wrists, ribbons and open-patterned knits.	
			5. Skin Care	
			-- Check skin around braces, casts, splints for redness, swelling, bruising, blisters daily.	
			-- Keep skin dry and clean.	

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			6. Exercise -- Swimming with gentle support is excellent exercise. -- Encourage reaching and playing with lightweight toys. -- Encourage infant to move any way he/she wishes and as much as he/she wishes. -- Infant should do respiration exercise such as blowing bubbles, toy pinwheels and blowing cotton. 7. Pain -- Tylenol for age and weight can be given. Do NOT give aspirin. -- Warm baths. -- Distraction from discomfort. 8. Dental Care -- Infant should begin seeing a dentist when first teeth erupt. -- Teeth brushing can be done with a wash cloth or small gentle tooth brush.	

NURSING CARE PLAN - OSTEOGENESIS IMPERFECTA

Assessment	Nursing Diagnosis	Goals	Plans	Initials Date Completed
			9. Prevent infection -- Wash hands before caring for infant. -- Avoid contact with individuals with known infection (cough, fever, nasal discharge, vomiting, diarrhea). -- Use Kleenex which kill bacteria/viruses. 10. Encourage parents to discuss concerns and questions. 11. Measure length, weight, arm and leg circumferences, and head circumferences monthly.	

RESOURCES

THE INFANT WITH PROBLEMS OF MOBILITY

1. American Brittle Bone Society
1256 Merrill Drive, Marshallton (215) 692-6248
Westchester, PA 19380

2. Osteogenesis Imperfecta Foundation, Inc.
P. O. Box 838 (603) 623-0934
Manchester, NH 03105

3. National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612

4. Eastern Montana College
Department of Special Education
Billings, MT 59101
(library resources and some consultants)

5. Rehabilitative Services Advisory Council
111 North Sanders (406) 444-2590
Helena, MT 59604

6. Child and Family Services

a. Region II Child and Family Services
1500 9th Avenue South (406) 452-9531
Great Falls, MT 59405

b. Family Outreach, Inc.
825 Helena Avenue (406) 443-7370
Helena, MT 59601

c. Developmental/Educational Assistance Program
Box 898 (406) 232-6034
Miles City, MT 59301

d. Developmental Assessment Services
East Little Street (406) 365-6031
Glendive, MT 59330

e. Hi Line Home Programs
P. O. Box 469 (406) 228-9431
Glasgow, MT 59230

7. Montana Center for Handicapped Children (406) 657-2312
Normal Avenue and Poly Drive
Billings, MT 59101

8. Montana Coalition of Handicapped
P. O. Box 4374
Missoula, MT 59806

9. Federation of Children with Special Needs
312 Stuart Street (617) 482-2915
Boston, MA 02116

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